FILLING THE LANGUAGE GAP:

THE FEASIBILITY OF COMMUNICATION RESOURCES USED IN THE PROVISION OF HEALTHCARE FOR HIV/AIDS AND TUBERCULOSIS IN THE EASTERN CAPE, SOUTH AFRICA.

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A thesis submitted in fulfilment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

at

RHODES UNIVERSITY

Prepared for:

African Language Studies, School of Languages and Literatures

Rhodes University

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12 December 2024

Declaration

I, the undersigned, Nathalia Lourenço declare that this thesis is my own work and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references. This work has not been submitted previously in its entirety, or in any part, at any other higher education institution for degree purposes.

…………………………….. 12 December 2024 ………………………………

Nathalia Lourenço Date

Acknowledgements

I would like to express my deepest gratitude to my colleagues, fellow students, family, and friends, who have supported me throughout my PhD journey and without whom this PhD would not have been possible.

Thank you to my supervisors, Dr Bulelwa Nosilela and Prof Patrick Luyten. I am grateful to you both for the knowledge you have shared with me, for your feedback and encouragement throughout all the steps of my PhD. Thank you also to my former supervisor, Prof Russell Kaschula, for your formative guidance and support in the initial stages of this research. I am grateful to have worked with and learnt so much from all of you.

Thank you to my wife, Vee Lourenço, for your unwavering support. Thank you for supporting me emotionally, practically, and academically: from giving me the encouragement to undertake this study, and giving me perspective during the challenges of this PhD; to doing all the big and small things in our life that made it possible for me to work on my studies; to your feedback on my writing, ideas, designs, and research plans. Thank you for your flexibility, for moving across countries with me, and for your confidence in me and my work.

Thank you to my family for your support. Thank you to my mother, Dr Carol Leff, for being an academic and real-world inspiration, for your advice with navigating a PhD, and for your professional proofreading services. Thanks also to my sister, Amy von Witt, for checking in on me and cheering me on. And thank you Dr Paul Mason, William von Witt, and Dr Cathy O'Shea for your support.

Thank you to my colleagues at KU Leuven: Ellen Berghmans, Simon Fiore, Rozemarijn Jeannin, Dr Saskia Malcorps, Dr Celine de Meulemeester, Dr Eileen Tang, Prof Nicole Vliegen, and Lara Wulleman. Being a part of this team has greatly enriched my PhD experience and my PhD itself. Thank you all for your suggestions, encouragement and advice; I have learnt a lot through working with you all. Thanks also to Lara for your feedback on my positionality statement, and to Celine for your in-depth assistance with the quantitative analysis.

Thank you to my research assistant Ziphozethu Salman for your flexibility with the fieldwork plans, for sharing your ideas, and for building the connections at healthcare sites that enabled this research to happen.

Thank you to the NIHSS network of support. Thank you to the regional mentors, Prof Fred Hendricks and Prof Kishore Raga, for your ongoing support in the NIHSS workshops, and to my initial mentor, Prof Paul Maylam, for your encouragement in the early stages of my PhD. Thank you to Prof Charlyn Dyers and Prof Thembinkosi Goniwe for your invaluable feedback on my written work. Thanks also to the fellow NIHSS students for your feedback during workshops, and for the supportive network you created.

Thanks to Prof Jennifer Watermeyer and Prof Ros Dowse for your academic and practical insights and advice. I am grateful for the knowledge you have shared, and to have had the opportunity to learn from you.

Thank you to Lungile, Wendy and Zimasa Dunywa. Thank you Lungile for sharing your insights into being a HCP in the Eastern Cape, to Wendy for your guidance on navigating the Eastern Cape healthcare research processes, and to Zimasa for your research assistance.

Thank you to my colleagues at Rhodes University, in particular Snethemba Mavuso and the CPGS writing group. Thank you Snethemba for being a valuable colleague, and for your insights and support; it was a pleasure to share this research journey with you. Thank you to Tsoholofelo Sepotokele and Hope Dube for your feedback on my writing, and for the encouraging atmosphere you created.

Thank you to Nichole de Vos, Christel Maes, Maïté Jacmin, Hannelie Rielly and Wendy Dyibishe for your administrative support at Rhodes University and the KU Leuven.

The financial assistance of the National Institute for the Humanities and Social Sciences (NIHSS), in collaboration with the South African Humanities Deans Association (SAHUDA) towards this research is hereby acknowledged. Opinions expressed and conclusions arrived at are those of the author and are not necessarily to be attributed to the NIHSS and SAHUDA.

This research has been supported by the financial assistance of VLIR-UOS. VLIR-UOS supports partnerships between universities and university colleges in Flanders (Belgium) and the Global South looking for innovative responses to global and local challenges. The funders had no role in study design, data collection and analysis, or preparation of the manuscript.

Abstract

South Africa has the largest number of Human Immunodeficiency Virus (HIV)-positive people in the world, the third-highest rate of Tuberculosis (TB) infections, and the second-highest rate of Multi-Drug Resistant TB (MDR-TB) globally, with up to 60% of HIV-positive healthcare users (HCUs) infected with TB as a co-infection. Both HIV/AIDS and TB require strict medicines adherence for disease management or treatment respectively; however, this is often not attained, and as such these statistics also represent lives affected by or lives lost to these diseases.

Moreover, in South Africa, up to 80% of healthcare consultations are conducted through a second language. Despite language policies suggesting the contrary, African languages are neglected in healthcare provision in South Africa. This perpetuates inequalities within the South African healthcare system by limiting HCUs understanding of and agency in their own healthcare and maintaining a barrier to more effective treatment. Such language barriers may also result in HCUs defaulting on treatment. Added to this, the fear and mistrust arising from language power dynamics contributes to high rates of avoidance behaviour.

This research therefore aimed to (a) explore how healthcare professionals (HCPs) and HCUs communicate when they are not fluent in the same language in care for HIV/AIDS and TB patients; (b) develop practical and feasible strategies that would enable HCPs to address language barriers in their consultations for HIV and TB and (c) to empirically evaluate these strategies in a pilot feasibility trial in the Eastern Cape. The first aim (a) concerning the problem of language barriers in healthcare consultations was addressed through identifying communication barriers experienced by HCPs in South Africa, exploring the strategies used to navigate or alleviate these barriers, creating and implementing communication resources, and analysing the effects of these resources on HCPs' communication. A selective narrative review was conducted (Chapter 2) to identify the main communication problems experienced by HCPs and HCUs, as well as the main communication strategies and resources used by HCPs to reduce these communication problems. This was further explored by conducting two needs analyses with HCPs (n=31) in South Africa, and specifically in the Eastern Cape, which revealed differing perspectives on health communication and confirmed HCPs' need for communication resources. For the second aim (b), existing communication resources were reviewed and selected or further developed following a Participatory Action Research approach, and then (c) empirically evaluated in a pilot feasibility trial with six healthcare sites in the Eastern Cape. Both the needs analyses and the pilot feasibility trial were adapted to employ an online or blended approach due to COVID-19-related limitations. The feasibility and acceptability of both the study protocol and the proposed communication resources were evaluated.

Three major findings emerged from this research. First, this research echoed existing literature confirming that HCPs do not have the support they need at a structural level. Second, while it was found that there is no one-size-fits-all solution for resources and training to improve HCP-HCU communication, it was noted that the most appropriate resources are those that are flexible, and those that support HCPs' language learning. HCPs who were already sensitive to communication barriers and were already taking steps to improve their second language (L2) proficiency also took initiative to use the resources in ways other than those suggested in order to best support the communication needs of them and the HCUs they consulted. Third, and linked to the second finding, it was found that communication resources that covered conditions including, but not limited to, HIV and TB were more appropriate. HCPs who used the resources showed a small, although not statistically significant, increase in communication satisfaction, satisfaction with resource support, and trust after using the resources for one month. Although implementation problems were encountered in some settings of the intervention, it was found that this intervention has the potential to be further evaluated in a larger, multi-site randomised controlled trial (RCT).

These findings inform recommendations which are made to improve the feasibility of such a study in order to conduct an RCT; to further develop the resources in order to enhance communication between HCPs and HCUs both in HIV and TB consultations and in other fields of healthcare; and to implement a similar intervention at the university level and as Continuing Medical Education. The insights gained into HCPs' support for language support resources, which resources were used, and particularly how they were used, are significant for taking actionable steps in supporting HCPs' provision of more equitable healthcare in multilingual South Africa.

Key words:
communication, feasibility study, healthcare, language barriers, public health

Table of Contents

List of acronyms and abbreviations

A&E	Accident and Emergency
AIDS	Acquired Immune Deficiency Syndrome
ANOVA	Analysis of variance
AR	Action research
ART	Antiretroviral treatment
ARV	Antiretroviral
CHC	Community Health Centre
CHW	Community healthcare worker
CME	Continuing medical education
CPD	Continuing professional development
CONSORT	Consolidated Standards of Reporting Trials
DoH	Department of Health
GP	General practitioner
HCP	Healthcare professional
HCU	Healthcare user
HoD	Head of Department
HIV	Human Immunodeficiency Virus
IPT	Isoniazid Preventive Therapy
L1	First language
L2	Second language
MDR-TB	Multi-Drug-Resistant Tuberculosis
MSM	Men who have sex with men
NDP	National Development Plan
NGO	Non-Governmental Organisation
OPD	Outpatient Department
OT	Occupational Therapist / Occupational Therapy
PAR	Participatory Action Research
RCT	Randomised controlled trial
RUESC	Rhodes University Ethical Standards Committee
STI	Sexually transmitted infection
TB	Tuberculosis
XDR-TB	Extensively Drug-Resistant Tuberculosis

Chapter 1: Introduction to language and healthcare in South Africa

1.1. Introduction

Access to healthcare services is a basic human right, and yet one that is not accessible for many people all over the world. In South Africa, every person has the right to healthcare services; however, the quality of the healthcare services one may receive is entangled in inequalities. One of the factors determining the quality of healthcare one receives is the language one speaks – even if it is an official, widely-spoken South African language. The South African healthcare system – and indeed the South African population – is strained by the impact of communicable diseases, particularly HIV/AIDS and Tuberculosis. Contrasts abound between inclusive language policies and their limited implementation (see for example Penn and Watermeyer, 2018: 172), and between the internationally impressive HIV/AIDS and TB responses (Abdool Karim et al., 2009: 926) and the continuing high rates of infection and drug resistance (Department of Health, 2015: 16).

Taking the form of participatory action research (PAR) and a pilot feasibility trial, this research project has explored how healthcare professionals in South Africa navigate language barriers (Chapters 2 and 4), taken actionable steps to explore resources that could be used to bridge these barriers (Chapter 6), conducted needs analyses (Chapter 5) and an intervention study (Chapter 7) to give new insights into healthcare communication, and made evidence-based recommendations to improve continuing medical education (CME) and policies for language and healthcare (Chapter 8).

This chapter begins with a general introduction to language barriers in South African healthcare, and an overview of the disease burden of HIV/AIDS and TB in South Africa (also noting the impact of the COVID-19 pandemic). This serves as a rationale for a study to improve health communication in HIV/AIDS and TB healthcare in South Africa. Thereafter the contexts of South Africa, the Eastern Cape, and its healthcare system are described, as a backdrop against which the rationale, questions and findings of the research can be understood. With this background established, the needs analyses and pilot feasibility studies are introduced, and the research problem, questions and objectives are stated. The significance of these combined studies is put forward, the positionality of the researcher is noted, and finally a more detailed outline of the chapters in this thesis is presented.

1.2. HIV/AIDS and TB in context: South Africa's struggle to offer appropriate care

The context of this research gives important insights into the surrounding circumstances, needs and constraints of the research. This can inform the appropriate approaches to designing and implementing the research, and the generalisability of the research findings. South Africa is a linguistically diverse country, with inequalities pervading the healthcare system, and with distinct contexts across provinces and urban, peri-urban and rural areas. This section does not purport to describe the context of the research in full detail, but rather gives an overview of these contexts in order to better situate the literature, research design and findings presented in the following chapters.

1.2.1. South Africa's sociopolitical and sociolinguistic context

Figure 1: Cover photograph by Johnny Miller from Time Magazine*, May 13 2019*

The above photograph, taken in South Africa, was the International cover page of *Time Magazine* in May 2019, with the headline "The World's Most Unequal Country". Inequalities pervade South African society on a variety of levels, in a variety of ways. This photograph depicts the suburb of Primrose, in Gauteng Province, South Africa, on the left, and across the road on the right, the informal settlement of Makause. The latest World Bank report on inequality in southern Africa showed that, still in 2022, South Africa remains the most unequal country in the world in terms of its Gini coefficient, or income per capita (Sulla et al., 2022: 1). Reflecting the inequalities inherited from apartheid, the income, opportunity, and access to basic services remain divided (largely) across racial lines. Furthermore, English (and to a lesser extent, Afrikaans) remains the language of political and economic power, and the language through which several public services are accessed – despite the fact that not all South Africans possess proficiency in this language.

South Africa has 11 official languages. The most recent General Household Survey (Stats SA, 2018a) looked at the languages most commonly spoken by people inside their home, and outside their home. This is illustrated below, including recognised (but not official) languages of the Khoi, Nama and San language group, and South African Sign Language:

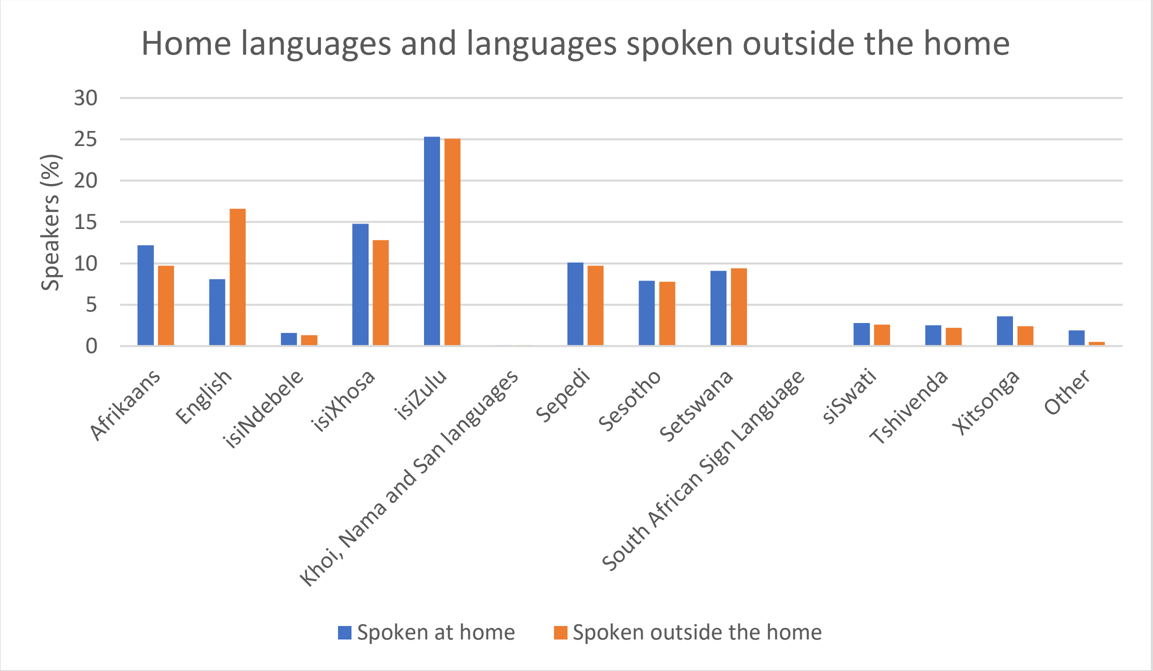


Figure 2: Home languages and other languages used in South Africa

This data shows that even though only 8% of South Africans speak English as their home language, double that number commonly use English for communication outside of their homes. It should be noted that many South Africans are multilingual, and therefore speak more languages other than their primary first language (L1) and the language they primarily use outside the home. Multilingualism is more prevalent in certain locations or contexts: people living in or around urban areas tend to be exposed to and speak a greater number of languages, while people living in rural areas or in more linguistically homogenous provinces may only speak their L1. And while English is the language commonly used in more official settings, not everyone is proficient in English, even if they are proficient in multiple other languages.

South Africa is divided into nine provinces: the Eastern Cape, the Free State, Gauteng, KwaZulu-Natal, Limpopo, Mpumalanga, the Northern Cape, North West, and the Western Cape. There are 25 languages spoken as a first language in South Africa, of which 11 are recognised as official languages. Each Province has about three official languages, with Gauteng province having most of these languages. This research, inclusive of the pilot feasibility trial, was conducted in the Eastern Cape, which has a language policy that recognises four languages: isiXhosa, English, Afrikaans and Sesotho.

1.2.2. Language barriers in South African healthcare

Language barriers compromise access to healthcare for a large portion of South Africa's population (Naidoo, 2014: 425). In South Africa healthcare professionals and HCUs often do not share a common language, with English and, to a lesser extent, Afrikaans, being the languages used most commonly by health professionals in formal settings (Watermeyer and Penn, 2009: 192). These languages are usually second languages or simply not spoken by the majority of HCUs using public healthcare in South Africa (Watermeyer and Penn, 2009: 192), with only 5% of doctors being able to conduct consultations in the HCU's home language at some healthcare sites (Schwartz in Penn and Watermeyer, 2018: 174).

Language barriers can impact people's access to healthcare and the quality of healthcare they receive. This is particularly in terms of increased avoidance behaviour when HCUs are unable to speak the language of their healthcare professionals (HCPs), or feel uncomfortable doing so (Naidoo, 2014: 425). These language barriers could even result in errors in diagnosis, errors in treatment, health education, and HCU compliance with health education (Deumert, 2010: 54).

Often (although not exclusively) nursing staff share the language and culture of the local population. This is not necessarily the case for other HCPs (such as doctors, surgeons, occupational therapists etc.), because of community service, internships and work placements, HCPs from other countries, and people moving to different provinces, and people who are from the province/area but do not speak the local language. As a result of this, nurses are often called upon to interpret for other HCPs.

1.2.3. Healthcare services and access

Public healthcare is available to all in South Africa, and exists alongside a private healthcare sector. It is estimated that around 24.3% of the population (Pretorius, 2017) – mostly middle class people – use private healthcare services, while the greater number of the population rely on the public healthcare system. The National Health Act (Republic of South Africa, 2003) affirms the right to free primary healthcare services for all people, except those who are covered by membership to a medical aid scheme.

Medical aid schemes are offered in South Africa, and it is through these that many people who use private healthcare have financial means to access these healthcare services. In South Africa, membership to medical aid schemes differs notably across races, with 72,9% of White, 52% of Indian/Asian, 17% of Coloured, and 9,9% of Black African individuals subscribed to a medical aid scheme (Stats SA, 2018a: 27). It should be kept in mind also that the demographics with the highest rates of membership are also minority demographics within the country. Only 10% of people in the Eastern Cape are members of a medical aid scheme (Stats SA, 2018a: 26) – the second-lowest provincial rate in the country.

In the Eastern Cape, three quarters (74,7%) of people typically visit a public clinic as their first healthcare facility if they are ill or injured; followed by a private doctor (17,6%), a public hospital (4,8%), or a traditional healer (1,1%) (Stats SA, 2018a: 26). As the first port-of-call in the public healthcare system, clinics are usually staffed by nurses and treat a broad spectrum of cases. Some clinics, known as Community Health Centres (CHC), are larger healthcare sites that are staffed by both doctors and nurses. When a HCU requires treatment beyond that which is available at a clinic or CHC, they are referred to a hospital. Hospitals are staffed by nurses, doctors and other HCPs, and treat HCUs who have been referred to the hospital, perform surgeries, and treat emergency cases. In the private healthcare system, people typically see a general practitioner (GP), and are referred to a private hospital if further treatment is required.

TB treatment in South Africa in the 1970s and 1980s was in-patient treatment for 12 or 18 months, and in the late 1980s was changed to ambulatory care (Abdool Karim et al., 2009: 924). The TB response was strengthened through a short-course programme, but this was hampered by the effect of the HIV epidemic on HIV-associated TB from the late 1990s onwards (Abdool Karim et al., 2009: 924). Although most TB care has been integrated into the general public hospitals, some specialised TB hospitals remain.

1.2.4. HIV/AIDS and TB in South Africa

South Africa is in many ways at the forefront of the HIV/AIDS and TB epidemics. South Africa has the largest number of people living with HIV globally, and this number continually increases (Department of Health, 2015: 16). South Africa also has the third highest TB rate, with the second highest rate of MDR-TB in the world (Department of Health, 2015: 18) and increasing rates of MDR-TB and Extensively Drug Resistant XDR-TB (Department of Health, 2015: 16). There has been progress in preventing and managing these diseases: antiretroviral therapy (ART) services have been scaled significantly, making antiretrovirals (ARVs) more accessible to people living with HIV/AIDS (Department of Health, 2015: 17); HIV/AIDS and TB mortality has declined (Department of Health, 2015: 16); South Africa was the first country in the world to start using bedaquiline for TB treatment (Department of Health, 2015: 36); and Isoniazid Preventive Therapy (IPT) is provided to all HIV positive healthcare users (HCUs) in an effort to decrease the risk of TB comorbidity (Department of Health, 2015: 17). While the cure rate for pulmonary TB HCUs has increased, the vast disparities between the provinces should be noted: only Gauteng and the Western Cape have been able to meet the targets set by the Department of Health (DoH), and the Eastern Cape has the lowest cure rate of TB in South Africa (Department of Health, 2015: 17). Furthermore, research on TB in South Africa is made difficult by the decentralised model of care, as well as poor infrastructure and limited resources (Penn and Watermeyer, 2018: 32).

TB infections in South Africa can be traced back to the 17th century, when TB was imported by settler colonists from Britain and Holland (Abdool Karim et al., 2009: 924). Infections then spread rapidly in the 19th century as a result of the mining industry in South Africa, where “large numbers of previously unexposed black South Africans [were exposed to TB] through poor working conditions, silica dust exposure, overcrowded hostels and poor nutrition” (Abdool Karim et al., 2009: 924). TB infections continued spreading throughout the 20th and 21st centuries, exacerbated by the unequal provision of healthcare services for

Black people and people of colour in South Africa under apartheid (Abdool Karim et al., 2009: 924).

The first cases of AIDS in South Africa were identified in 1982 and were, similar to AIDS outbreaks in other parts of the world, identified in men who have sex with men (MSM) (Abdool Karim et al., 2009: 922). Also similar to the AIDS response in other parts of the world, AIDS was thought to only affect the homosexual male community and was met with homophobia and complacency (Abdool Karim et al., 2009: 922). Even though this subtype of HIV (subtype B) continued to spread among MSM, it was in the late 1980s that subtype C became dominant, affecting the general population with an exponential increase in infection rates (Abdool Karim et al., 2009: 922). After the homophobic response to label subtype B as a 'gay disease', the apartheid government's response to subtype C was to label it as a 'black disease' (Abdool Karim et al., 2009: 922) – thus continuing to ignore an epidemic affecting the country's population.

However, after apartheid and subsequent continued AIDS-denialism (discussed in more detail in Chapter 2), South Africa has implemented large-scale responses to TB and HIV/AIDS:

> Both the TB and HIV epidemics have served as key drivers of innovation in service delivery, monitoring and evaluation. The TB control programme has established of a national electronic register that facilitates standardized recording and reporting and evaluation of the national TB programme. HIV treatment programmes have taken this one step further to collect longitudinal data on the clinical status, drug switching, drug-related adverse events, treatment adherence, CD4 cell count and viral load measurements and treatment outcomes. (Abdool Karim et al., 2009: 926)

The strengths of the systems in place for HIV and TB testing in South Africa were highlighted in the country's response to the COVID-19 pandemic. Clinical laboratories in South Africa have "substantial capacity to perform high throughput PCR assays for HIV viral load (more than 50,000 tests per day)", (Abdool Karim and Abdool Karim, 2020: 367), and the community outreach networks developed for TB were utilised for COVID-19 contact tracing and quarantine monitoring (Abdool Karim and Abdool Karim, 2020: 367).

1.2.5. HIV/AIDS and the COVID-19 pandemic in South Africa

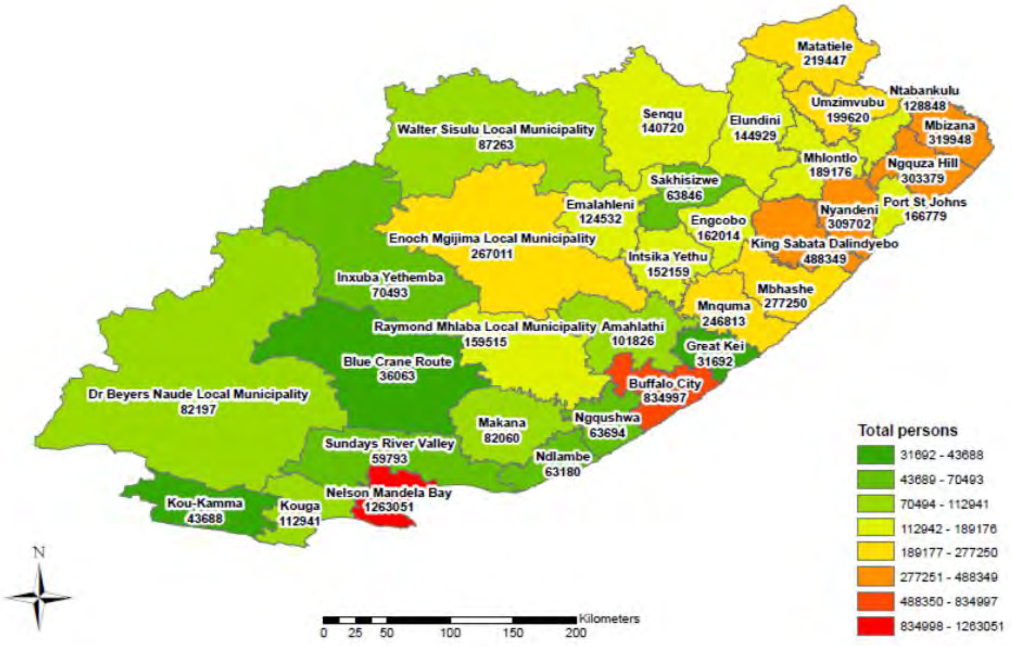
At the start of the COVID-19 pandemic there was great concern about the potential for people living with HIV/AIDS and/or TB to be more susceptible to contracting severe COVID-19. While it became apparent that diabetes had a significant effect on COVID-19 mortality, with 52% of COVID-19 deaths having diabetes as a comorbidity, HIV/AIDS and TB comorbidities made up for relatively smaller number of deaths, i.e. 12% and 2% of COVID-19 deaths respectively (Abdool Karim and Abdool Karim, 2020: 367). However, the lockdowns implemented in response to the COVID-19 pandemic had a notable impact on HIV/AIDS and TB diagnosis, care and treatment.

While the number of ART collection visits remained stable, HIV testing decreased by an estimated 47.6%, ART initiations decreased by an estimated 46.2%, and TB PCR testing decreased by an estimated 59% with South Africa's first lockdown in April 2020 (Dorward et al., 2021: e158; Abdool Karim and Abdool Karim, 2020: 366), with the decreases most pronounced in urban areas (Dorward et al., 2021: e163). ART collections decreased in the first month of lockdown, but quickly returned to pre-lockdown levels the following month (Dorward et al., 2021: e164). HIV testing and ART initiations gradually increased over the following three months as the lockdown restrictions were gradually eased (Dorward et al., 2021: e163). TB and COVID-19 are respiratory infections with similar symptoms and the propensity to spread more easily in conditions of poverty where physical distancing is more difficult to implement (Abdool Karim and Abdool Karim, 2020: 367). This meant that community outreach methods of contact tracing and quarantine monitoring already established for South Africa's TB epidemic could be adapted for the COVID-19 pandemic (Abdool Karim and Abdool Karim, 2020: 367). In addition to concerns for personal health during the pandemic (especially due to lack of personal protective equipment and limited capacity for physical distancing in clinics), limited clinic opening times, and increased difficulties to reach clinics (e.g. restrictions on movement and travel), 28 000 HIV CHWs (community healthcare workers) were reassigned to COVID-19 screening (Dorward et al., 2021: e158, Abdool Karim and Abdool Karim, 2020: 367). It is recommended that "After lockdown, and in any future COVID-19 restrictions, strategies to catch up with HIV testing and increase ART initiation should be implemented, alongside efforts to maintain treatment provision." (Dorward et al., 2021: e159). An important part of this could include integrating existing community engagement and outreach for HIV/AIDS and TB with the COVID-19 response (Abdool Karim and Abdool Karim, 2020: 367), rather than replacing one with another.

1.2.6. Eastern Cape Province: The research site

The Eastern Cape was the province with the highest inequality in 2015 (Stats SA, 2020, more recent statistics not available). It is the third most populous province in the country (Stats SA, 2018: 1), and has three main languages: isiXhosa, Afrikaans and English, spoken as home languages by 82,7%, 10,3% and 3,9% of the Eastern Cape population respectively (Stats SA, 2018: 18). The government of the Eastern Cape is subdivided into two metropolitan municipalities and six district municipalities.

The two districts focused on in this research are the Buffalo City district municipality and the Nelson Mandela Bay district municipality. These municipalities have the two largest cities, which are East London in Buffalo City and Gqeberha in Nelson Mandela Bay. These are two geographically small, yet relatively densely populated metropolitan municipalities. The population of Buffalo City is 834 997 and the population of Nelson Mandela Bay is 1 263 051 (Stats SA 2018: 8).



Picture 1: Map of Eastern Cape population by municipality (Community Survey, 2016: 10)

The racial makeup of Buffalo City is 86% Black African, 6,7% Coloured, 0,9% Indian/Asian, and 6,9% white. The racial makeup of Nelson Mandela Bay is 59,9% Black African, 23,9% Coloured, 1,2% Indian/Asian, and 15% White (Stats SA 2018: 15).

The two districts focused on in this chapter are not necessarily representative of the Eastern Cape; rather, they represent some of the most urbanised parts of a largely agricultural province. In order for future research such as this to be more representative, more rural districts should be included. Healthcare sites in other districts were approached to participate, but were not included in the final research. These were harder to reach, for details that are outlined in the feasibility chapter.

1.3. Research problem

The problem motivating this research comprises two distinct but interlinked parts. Firstly, unequal access to healthcare in a post-apartheid society is perpetuated by insufficient practical support for the use of African languages in healthcare. Even though in South Africa, as noted, 11 languages are constitutionally recognised as ‘official’, yet healthcare services often remain linguistically inaccessible for speakers of African languages due to insufficient practical efforts. In cases where HCPs do not speak a language in which an HCU is fluent, HCUs understanding of and agency in their own healthcare is limited.

Secondly, many HCPs do not have sufficient or effective resources, training, and/or strategies to address the negative impact of communication barriers in healthcare. The focus of this is particularly on HIV/AIDS and TB in South Africa given the high disease burden in the country, and the necessity of good HCP-HCU communication for counselling and ultimately for increased medicines adherence.

1.4. Research questions

The research undertook to answer the following research questions:

1. How do healthcare providers and healthcare users communicate in HIV/AIDS and TB healthcare consultations when they are not fluent in the same language?
2. What communication resources and training are appropriate for the provision of HIV/AIDS and TB healthcare in South Africa?
3. How feasible is it to implement and measure the suggested resources and training?
4. What are the effects of the suggested communication resources and training in healthcare provision?

1.5. Research objectives

1. To identify the main communication problems experienced by healthcare providers and healthcare users.
2. To identify the main communication strategies used by healthcare providers and healthcare users.
3. To create and implement communication resources and training to be used by healthcare professionals in the provision of HIV/AIDS and TB consultations.
4. To analyse the effects of the communication models in terms of feasibility of implementation and satisfaction in a pilot feasibility trial.

1.6. Significance of the studies

These studies are significant for two main reasons: their context-responsiveness, and the role in reducing the HIV/AIDS and TB disease burden in the South African context through communication strategies.

The context-responsiveness of these studies is put into practise through the lens of Hulsman's goal-oriented theory (as described in Chapter 3), and through the methodological approach of PAR (detailed in Chapter 4). This merging of the theoretical and empirical research resulted in 'practical knowing' (Munn-Giddings, 2021: 87) that has significance both in an academic context and in a "real-world" context. Adding to the significance of these studies in this regard is the variety of contexts that were included, including HCPs in a variety of healthcare roles and settings. The context-responsiveness can be seen, for example, in the shift during this research from an initial or intend focus on only HIV/AIDS and TB, to a broader intervention which included, but was not limited to, these diseases. This was a direct result of feedback from participating HCPs, whose needs were not isolated, but rather, part of a broader context. This context-responsiveness also included an awareness of the impact of Covid-19 during the course of these studies.

The prevalence of HIV/AIDS and TB in South Africa is well documented, and the literature illustrates the impact of language barriers in healthcare provision in South Africa. Several interventions have been implemented to support healthcare communication, with varied success. These studies addressed the urgent need for sustainable and feasible support for HCP-HCU communication. The intervention trialled in this research project contributes to the improvement of HCP-HCU communication. Following the goals framework (fig. 5, Chapter

3), this improvement constitutes a secondary goal, and a necessary part of a set of goals through which a reduced HIV/AIDS and TB disease burden could be attained.

1.7. Positionality statement

When conducting research, the positionality of the researcher can impact how research is conceptualised, how relationships are built and interactions occur in the field, and how data is analysed (Dryden-Peterson, 2020). This positionality statement aims to situate me, the researcher, within an intersectional lens which acknowledges "the interplay between structures and institutions at the macro-level, and identities and lived lives at the micro-level" (Christensen & Siim, 2006 and Jensen, 2006, in Christensen and Jensen 2012: 110). By positioning myself on the intersections of race, gender, language proficiencies, and healthcare experiences, this positionality statement aims to offer some insights into how the macro and micro social constructions within which our realities are shaped may have impacted this research.

I am a white, cisgender, queer woman in her early thirties, who grew up primarily in the Eastern Cape and is socioeconomically located in the stable middle class[1]. My home language is English, and this is the only language I can speak fluently. I learnt some isiXhosa informally in high school, and then majored in isiXhosa Non-Mother Tongue at university in the Eastern Cape. Growing up and as an adult I have been subscribed to a medical aid scheme, and thus have used the private healthcare system in South Africa. I became aware of TB from an early age: when I was six years old my BCG vaccination was administered incorrectly[2] and I developed a BCG abscess which was surgically lanced and drained, after which I took TB medication for six months. Many years later, my mother contracted pulmonary TB and was treated through the public healthcare system in the Eastern Cape. On the other hand, I do not have such first-hand experience or close second-hand knowledge of living with HIV/AIDS and receiving treatment through the Eastern Cape healthcare system.

The value of positionality and its potential impact on research lies in the interaction between the researcher and the research participants. In the South African context, this means the involvement of participants from diverse gender, racial, social, educational, linguistic, and

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[1] The socioeconomic class category used here is based on the definitions given by SA-TIED (2019).

[2] This was an isolated event.

ethnic backgrounds, who play a role in facilitating or impeding opportunities to access information in relation to the above-mentioned positionality (Hoogendoorn & Visser, 2012). As such, the positionality of research participants is also described in each study presented in this research.

1.8. Chapters outline

In Chapter 2 the relevant existing literature is reviewed in order to position this research within the existing body of work and in relation to established theories on health communication. The literature on HIV/AIDS and TB in South Africa is detailed; South Africa's socio-political landscape is described; and health communication is explored in detail, considering communication barriers, health literacy, terminology, and interpreting.

The theoretical and conceptual frameworks of this research project are then explained in Chapter 3, presenting a goal-oriented theory to frame this research.

In Chapter 4, a mixed-methods methodology is presented, and the research design clarifies the appropriacy of the two overarching and intertwined methodologies of PAR and a pilot feasibility trial. These methodologies are explained, and their application to this research is detailed.

Using the methodology of PAR, two small pilot studies were conducted as needs analyses, and these are described in Chapter 5. This chapter includes the presentation and analysis of the data from both studies, and combines the findings to present the health communication needs of participants in order to inform the pilot feasibility trial.

Following the participatory approach of this research, health communication resources were sourced and developed; this is described in Chapter 6. Existing health communication resources were scoped and are summarised in this chapter, whereafter the selection, adaptation and development of the resources used in the pilot feasibility trial are detailed. In order to evaluate the efficacy of these resources a randomised controlled trial (RCT) is recommended; in preparation for this a pilot feasibility trial was conducted.

Chapter 7 therefore investigates feasibility of conducting a waitlist-controlled cluster-randomised trial in which HCPs used the resources for two months. The findings from the literature, the needs analyses and the pilot feasibility trial are then reflected on in Chapter 8, which supports recommendations that are made for a full RCT, for policy, for higher education, and for continued medical education.

1.9. Conclusion

This chapter has introduced the healthcare communication context of South Africa in terms of language barriers, the burden of HIV/AIDS and TB, and the importance of communication between HCPs and HCUs in the management of these diseases. The research problem, research questions and research objectives have been presented, outlining how communication barriers will be explored and addressed through this research. The positionality of the researcher has been described, and further context specific to healthcare in the Eastern Cape, South Africa, has been presented. The research problem and research context will be explored in more detail in the literature review presented in Chapter 2, whereafter the following chapters will describe the studies undertaken to address the research problem.

Chapter 2: Literature Review

2.1. Introduction

In a country at the coalface of the HIV/AIDS and TB epidemics, an unequal healthcare system is exacerbated by language barriers, which in turn perpetuate an outdated Western biomedical model that does not serve the people it treats. This chapter outlines the literature on health communication, with specific reference to communication within HIV/AIDS and TB healthcare in South Africa. This chapter comprises three key areas of focus: South Africa's socio-political landscape, health communication, and HIV/AIDS and TB in South Africa. Within each of these focus areas, subthemes are addressed.

This chapter begins by describing healthcare and disease in South Africa, including subthemes such as the way in which South Africa is at the forefront of the HIV/AIDS and TB epidemics; the importance and influencing factors of medicines adherence; and the role and context of healthcare sites in South Africa is described. To background why health communication remains a challenge in South Africa, a summary of health communication training is given, including both in-service and university-level training.

Once the contexts of HIV/AIDS, TB, healthcare sites and health communication training have been described, this chapter critically examines South Africa's socio-political landscape through the subthemes of the legacy of post-apartheid inequality; government language policies; and, given the important role culture plays in a society as multi-cultural as South Africa, the cultural and psycho-social factors involved in healthcare are also described in this section, and the way in which culturally-appropriate modes of communication may differ between health practitioner and HCU are introduced.

Health communication is then described and expanded upon, through the subthemes of barriers to communication in South African healthcare; the impact of communication on health outcomes, HCU satisfaction, HCU understanding and medicines adherence is illustrated; the role of culturally-responsive written and non-verbal communication; and the possibilities and realities of medical interpreting.

This chapter takes the form of a selective narrative literature review, where literature has been identified and selected based on its relevance to this research project, with a focus on strategies, resources and training to overcome language and communication barriers between

HCPs and HCUs in the provision of HIV/AIDS and TB healthcare. The literature selected for inclusion in this chapter has intentionally favoured South African researchers, as the importance of context when considering any type of communication intervention cannot be understated. This chapter expands on the context outlined in the Introduction chapter and paints the academic landscape through which the research questions may be understood, and upon which the resources, training and intervention of this research project could be built.

2.2. South Africa's socio-political landscape

South Africa is a multilingual country; however, English is the predominant language used to access healthcare. Each province recognises English and the most dominant African language(s) in that province. Yet despite this, most people in South Africa do not have access to English. This is one of the reasons why there is no discourse competence in the languages used by both HCPs (who have been taught in English as a language of teaching and learning) and HCUs (who might not have been educated in English, and use their indigenous languages). This research is therefore interested in communication barriers experienced by HCPs and HCUs in their real-world contexts, which are inextricably linked to their socio-political landscape. In order to better understand how and why these barriers are experienced, and to consider what interventions could be most appropriate and feasible, the socio-political landscape of South Africa is presented here.

2.2.1. Political and linguistic landscape

The significant racial and socioeconomic inequalities of apartheid were inherited by South Africa's democracy in 1994 (Myburgh et al., 2005: 473), and still permeate South African society today as people's freedom, development and health remain constrained (Chasi, 2014: 12). Included in this apartheid legacy of inequality is South Africa's healthcare system. As described by Van Rensburg and Fourie (1994: 98) at the dawn of South Africa's democracy, the South African healthcare system was originally built (a) without a central healthcare policy, (b) with the purpose of supporting white minority access, and (c) within an economic free-market system that supported profiteering. While much has of course changed in the past 30 years, it should also be borne in mind what the current healthcare system grew from and, in many ways, had to fight against.

Around 71% of South Africans depend on public healthcare services (Statistics South Africa in Penn and Watermeyer, 2018: 28). There is a shortage of health professionals, most notably in rural areas in South Africa, and many health professionals have emigrated or are emigrating (Penn and Watermeyer, 2018: 28). South Africans experience socio-economic and interactional barriers to healthcare: HCUs' financial means limit their ability to access healthcare, as even when healthcare is free there remain financial barriers such as transport costs, and so-called "unproductive patient-provider interactions" (Goudge et al. in Deumert, 2010: 53) result from poor communication between healthcare practitioners and HCUs (Deumert, 2010: 53). In this way, access to healthcare is still dependent on race and socio-economic status (Deumert, 2010: 54; Kilian et al., 2014: 160).

a) Satisfaction

Language service quality and HCU and staff satisfaction is not necessarily linked to access to resources, the type of training received by staff or the level to which they are trained, or job security (Penn and Watermeyer, 2018: 199). Rather, these attributes are closely linked to the relationships among staff (Schwartz in Penn and Watermeyer, 2018: 199) and how they perceive the different roles and functions within health interactions (Penn and Watermeyer, 2018: 199). Of particular importance is establishing secure, long-term partnerships through having staff work together regularly such that they can build good working relationships (Penn and Watermeyer, 2018: 199). Obstacles to establishing these partnerships can include difficulties and frustrations with workloads and space, and systemic frustrations (Penn and Watermeyer, 2018: 200).

In South Africa, HCUs reported 80.3% satisfaction with public healthcare, and 97.6% satisfaction for private healthcare[3]; however only 53.8% of HCUs were 'very satisfied' with public healthcare services, compared to 92.6% of private healthcare users (Stats SA, 2018b: 25). This is representative of the Eastern Cape too, with 58.8% versus 95.5% of HCUs 'very satisfied' with public and private healthcare respectively (Stats SA, 2018b: 25).

In the case of South Africa, where language barriers permeate public health provision, these barriers may "pose challenges in terms of achieving high levels of satisfaction among medical professionals and patients, providing high-quality healthcare and maintaining patient safety" (Al Shamsi et al., 2020: e122). There is limited research outside of the United States on HCU satisfaction and their perceived quality of healthcare given by healthcare

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[3] 'Satisfaction' here refers to responses of 'Very satisfied' and 'Somewhat satisfied', the highest ranking levels of satisfaction on the five-point Likert scale used in the study.

practitioners (Myburgh et al., 2005: 473). In a nationwide household study on HCU satisfaction with HCPs in South Africa, Myburgh et al. (2005: 476) found that White HCUs and HCUs with high socio-economic status were 3.5 times more likely to report that they had received excellent services than Black African HCUs and HCUs with low socio-economic status. Considering English as a language of power and hegemony in South African healthcare provision, HCUs' reporting of excellent service could also be attributed to the HCUs sharing the linguistic background of the HCPs; sharing the culture of the HCPs; and, related to this, experiencing a lesser degree of HCP-HCU power dynamics. Furthermore, while one cannot definitively correlate HCU satisfaction with quality of care received, these results paired with the racial and socio-economic context in South Africa and the disparities in healthcare services may well reflect the inequality in healthcare provision in South Africa (Myburgh et al., 2005: 476).

b) Language as a barrier

Like most other African countries in which the former colonial languages of English, French or Portuguese are the official or dominant languages, language barriers often separate service providers, in this case healthcare practitioners, from the clients, or in this case HCUs as 60-80% of populations are not fluent in these languages. (Chumbow in Haricharan et al., 2013: 58; Moyo and Salawu, 2017: 103). As stated by Al Shamsi et al. (2020: e122) "Health disparities such as unequal treatment related to language barriers are associated with unequal access to healthcare and unequal health outcomes". Such language barriers impact the quality and cost of healthcare, with HCUs more likely to experience adverse events as a result (Al Shamsi et al., 2020: e122).

While South Africa's post-1994 constitution gave recognition to 11 official languages, no structures or provisions were made for new interpreting positions to accommodate this (Drennan and Swartz, and Beukes in Haricharan et al., 2013: 58). Most healthcare practitioners in South Africa do not speak the languages of the HCUs beyond English and Afrikaans (Kilian et al., 2014: 159). As much as 80% of healthcare consultations in South Africa are done across language barriers (Penn in Haricharan et al., 2013: 58), disproportionately affecting Black South Africans who use public healthcare and are not proficient in English or Afrikaans (Kilian et al., 2014: 160).

Earlier post-apartheid literature on health communication in South Africa often explored the communication of English- or Afrikaans-speaking HCPs in healthcare sites that catered to an increasing number of isiXhosa-speaking HCUs (see for example Crawford (1999) and Deumert (2010)). However, the communication explored in this research differs in that it explores communication in the Eastern Cape in healthcare sites that have historically also catered to isiXhosa-speaking HCUs.

c) *Existing health communication training*

In Crawford's study (1999: 34), she found that there were lunchtime isiXhosa classes offered at some teaching hospitals, but that they were not well attended and did not have high success rates. This was not due to lack of interest but rather that health professionals would have liked to learn isiXhosa to better serve their HCUs, but they did not feel like they were making adequate or real progress (Crawford, 1999: 34). More than twenty years later there are still similar frustrations with language and communication in healthcare.

Penn and Watermeyer (2018: 232), two of South Africa's leading health communication researchers, designed a course on health communication for third-year medical students at a South African university. They received mixed feedback on the course, with the greatest interest coming from students who spoke a home language other than English, while many students who spoke English as their home language became impatient with the course as they believed it detracted from the scientific basis of their curriculum (Penn and Watermeyer, 2018: 232). This illustrates the language attitudes of the students and the effects of language prestige: the language of the HCU is seen as of lesser importance, with an expectation for HCUs to adapt to the language of the HCP, rather than the other way around. When there was a change in leadership at the medical school the course was suspended, and has since been minimally included as part of a first-year course (Penn and Watermeyer, 2018: 232).

Penn and Watermeyer (2018: 327) have identified the different models of health communication training offered at three of South Africa's main medical schools: some included basic second language courses for African languages early in the curriculum, taught alongside health psychology or sociology and offered by university departments external to the medical school. They found that clinical evaluation is taught using international checklists, such as the Calgary Cambridge communication guide, which is not localised to the South African context (Penn and Watermeyer, 2018: 327). The outcomes of these courses are broad and communication skills are often seen as ‘soft skills’ (van Staden et al. in Penn and Watermeyer, 2018: 327).

Even when the importance of communication training in healthcare is recognised, the models used to implement such training often do not consider cultural diversity or the appropriacy of the training for the context of the healthcare practitioners (Penn and Watermeyer, 2018: 323). While a one-year course teaching an African language is better than no communication training, it is insufficient to equip students to express themselves in that language, or “to understand much beyond a crude first level of enquiry from their patients” (Crawford, 1999: 34). Many students have not found courses like these useful, either because of the content covered, or because the students had no certainty of which language would be spoken by their HCUs in the location where they would end up working (Penn et al. in Penn and Watermeyer, 2018: 327). These students would have preferred on-site language training, especially in cases where there is a predominant language in the geographical area in which they would work (Penn et al. in Penn and Watermeyer, 2018: 327). When considering on-site communication or language training, any such intervention needs to show awareness of the possibility that organisations may view education as a more cost-effective solution to communication barriers, rather than also investing in the language services needed at the sites (Penn and Watermeyer, 2018: 327).

Rather than focusing on building fluency in a language or having a once-off course in cultural competence, healthcare courses should include imbedded, culturally-relevant and context-responsive courses to expose students to diversity such that they will be able to accommodate and adapt to diversity in different working contexts (Penn and Watermeyer, 2018: 332). In this case a course on health communication need not be language-specific, but rather equip students with a sensitivity to socio-cultural barriers and with the tools to work through these barriers (Penn and Watermeyer, 2018: 332). This learning can be extended beyond university and included on-site and be tailored to specific diseases, methods and contexts (Penn and Watermeyer, 2018: 333).

2.2.2. Government policies and implementation

Throughout South Africa’s history of colonialism and apartheid, White people received good quality healthcare while people of colour were systematically denied such care (Moola, 2019: 176):

> The South African government, through its apartheid policies, developed a health care system which was sustained through the years by the promulgation of racist legislation and the creation of institutions such as political and statutory bodies for the control of the health care professions and facilities. These institutions and facilities were built and managed with the specific aim of sustaining racial segregation and discrimination in health care. (South Africa, African National Congress, 1994)

As indicated in the ANC's National Health Plan (African National Congress, 1994), South African healthcare policies and initiatives have aimed to redress the inequalities upheld by the healthcare system under apartheid, and include policies ensuring free primary healthcare and exemptions from hospital fees (Deumert, 2010: 53). This has also included focus on HCU empowerment, for example the emphasis on service delivery in public sector institutions in the Batho Pele ('People First') (1997) principles is aligned with the South African constitution (Deumert, 2010: 53). South Africa's National Development Plan (NDP) has nine long-term health goals, relating to improving the health of the population and with strengthening the health systems (Department of Health, 2015: 21). This also includes a goal to improve TB prevention and cure by 2030 (Department of Health, 2015: 21). The NDP highlights some of the interventions needed, but does not make reference to the role of language in these interventions (Department of Health, 2015: 21). The Department of Health (2015: 36) has identified key challenges in HIV/AIDS prevention and reduction to include improved preventative programmes in order to decrease the rates of new infections, increasing the number of people enrolled in ARV treatment, and improving HCU retention.

ARVs were only approved for public provision in 2003 (Watermeyer and Penn, 2009: 192). By 2016 56% of people with HIV were enrolled in ARV treatment (UNAIDS, 2019). The delayed recognition of and action on HIV/AIDS by the South African government can be attributed to: the apartheid government's limited interest in caring for members of the population who were not White heterosexuals, and their belief that HIV/AIDS would not affect this population group; former president Nelson Mandela's minimal direction of the media and public agenda towards HIV/AIDS; and former president Thabo Mbeki's "dissident positions" (Chasi, 2014: 35) on HIV/AIDS and the failure of his administration to effect treatment regimens (Chasi, 2014: 35–36; Moola, 2019: 182); and the misinformation surrounding HIV/AIDS management practices espoused by former president Jacob Zuma (Moola, 2019: 182). Influenced by Mbeki's position, some people living with HIV/AIDS refused Western treatment as a means of recognising the effect apartheid and racialised

poverty had on Black people's health and suffering, and nationalistically rejecting the medicines associated with White people and Western medicine (Chasi, 2014: 19).
The Department of Arts and Culture's National Language Policy aims to promote the use of all 11 official South African languages in the provision of government services (Penn and Watermeyer, 2018: 172). In order to do this, government structures are responsible for providing services in each person's language of choice, and to train and provide access to interpreters to facilitate this (Penn and Watermeyer, 2018: 172). Furthermore, the Patients' Rights Charter (2002) and the National Health Act (Republic of South Africa, 2003) are more specific about HCUs' rights to access healthcare, including information about their health status and their different treatment options, in a language they understand and in a manner appropriate for the HCU's literacy levels (Deumert, 2010: 55; Naidoo, 2014: 425). While the legislation itself is impressive, it is limited by a lack of health literacy among South Africans, and a lack of realisable strategies to improve health literacy (Mokwena, 2015: 197). These documents do not specify how this could be made feasible and implemented (Deumert, 2010: 55). The Committee on the Rights of Persons with Disabilities expounds the South African government's obligation to provide interpreting services for d/Deaf[4] people, but also allows for costs to be considered as a reasonable cause to not implement such services (Haricharan et al., 2013: 64).

Out of all the developing countries South Africa has the highest health expenditure; however its outcomes are worse even than some of the lower-income countries (Global Health Initiative Strategy in Penn and Watermeyer, 2018: 28). Sixty percent of the health budget is allocated to human resources, and yet staff shortages are a constant battle, most notably in the rural and remote areas (Penn and Watermeyer, 2018: 28). The mismatch of expenditure and results could be attributed to poor implementation of what are generally good healthcare policies (Penn and Watermeyer, 2018: 28). South Africa's healthcare system has been criticised for "weak governance, ineptitude, poor coordination, corruption and negative healthcare professional attitudes" (Coovadia et al., McIntyre and Ataguba, and Rispel et al. in Penn and Watermeyer, 2018: 28).

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[4] The term d/Deaf encompasses deaf people defined as people with hearing loss or hearing difficulties as well as Deaf people defined as people who identify as part of a Deaf community of practice.

Language policies throughout sub-Saharan Africa still favour the formal colonial languages, despite 60-80% of the populations in these countries not being able to speak these languages, and it is because of this that Chumbow (in Haricharan et al., 2013: 58) argues the Millennium Development Goals are not being reached. As argued by Haricharan et al. (2013: 64) with regard to d/Deaf people, compromised access to healthcare information and communication equates to a violation of people's right to health; this argument could well be extended to include HCUs who receive healthcare in a language they cannot understand. Implementing strategies to improve communication across language barriers is of great importance in a society as multilingual and multicultural as South Africa, especially where high rates of HIV/AIDS necessitate that healthcare practitioners help ensure adherence to ARVs (Watermeyer and Penn, 2009: 193). While research is being done on the influence of language issues in healthcare, Oppenheimer and Bayer (in Penn and Watermeyer, 2018: 173) argue that this issue is still underexplored.

South Africa's Department of Health has implemented compulsory community service for healthcare practitioners, meaning that some health professionals are sent to remote or rural hospitals where they cannot speak the language(s) used by the HCUs in that area (Penn and Watermeyer, 2018: 175). Because of the geographical distribution of South Africa's languages, this means that even people who are fluent in indigenous South African languages may end up working in a part of the country where languages other than the ones they know are used. Recommendations have been made for increased access to interpreters in South African healthcare centres; however, these recommendations have not been fulfilled due to insufficient resources and infrastructure (Levin in Watermeyer and Penn, 2009: 193). The South African health sector employs very few professional interpreters and translators, attributed largely to the costs and bureaucracy involved and ineffective implementation (Crawford, 1999: 40; Moyo and Salawu, 2017: 103; Penn and Watermeyer, 2018: 173). Interpreting qualifications and accreditation systems in South Africa are not standardised (Penn and Watermeyer, 2018: 173), and when interpreting services are available at healthcare sites the interpreting is often done by untrained or inexperienced interpreters (Moyo and Salawu, 2017: 103). In several cases medical staff, nurses, general staff, and HCUs' family members fill the role of interpreter (Hussey in Moyo and Salawu, 2017: 103).

2.2.3. Ethnorelative practice

In order to communicate effectively, healthcare practitioners need to integrate their culture with that of the HCU and that of the healthcare centre (Kagawa-Singer and Kassim-Lakha, 2003: 578). The ability to recognise and integrate these cultures is known as ethnorelative practice (Kagawa-Singer and Kassim-Lakha, 2003: 578). The healthcare practitioner's understanding of the HCU's culture is not only important in terms of interpersonal communication and mutual respect, but also in terms of the healthcare practitioner's ability to deliver effective healthcare for the HCU. Each culture holds its own understanding of what health looks like and how it should be treated, and understanding this is vital for a healthcare practitioner to provide healthcare for their HCUs (Kagawa-Singer and Kassim-Lakha, 2003: 578). The necessity for ethnorelative practice can be understood as follows:

> New strategies are required to expand medical training to adequately address culturally discordant encounters among the physicians, their patients, and the families, for all three may have different concepts regarding the nature of the disease, expectations about treatment, and modes of appropriate communication beyond language. (Kagawa-Singer and Kassim-Lakha, 2003: 577)

a) Western biomedicine

Western culture is often seen as 'neutral' or the default position in many aspects of society: "These Eurocentric beliefs and values are rarely seen as culturally bound, and their universal applicability is assumed" (Kagawa-Singer and Kassim-Lakha, 2003: 580). Western biomedicine and bioethics are based on Western European-American cultures and understandings and conceptions of health (Kagawa-Singer and Kassim-Lakha, 2003: 580; Van Rensburg and Fourie, 1994: 98). Given the variety of different cultures participating in South Africa's healthcare system, the question of intercultural communication needs to be given great consideration, still beyond that which is included in this thesis.

HCUs often expect healthcare practitioners to speak to them in a direct manner, diminishing any expectation for active participation in a healthcare consultation (Penn and Watermeyer, 2018: 249). This expectation is further reinforced by the history of oppression under apartheid, where HCUs – especially Black African HCUs – were denied agency or opportunities for initiative (Penn and Watermeyer, 2018: 29), as well as cultural norms in many South African communities of practice where it is considered disrespectful to question a person in a position of authority, or to reveal a lack of understanding (Watermeyer and Penn, 2009: 192). The communication style of the healthcare practitioner is also typically more direct in cases where an interaction takes place in a language that is not the first language of either person (Penn and Watermeyer, 2018: 249). HCUs sometimes choose to answer healthcare practitioners with affirmative responses to avoid being ridiculed or angering the healthcare practitioner, and the lack of understanding behind these affirmative answers is often ignored because healthcare practitioners feel pressure to complete consultations quickly (Deumert, 2010: 57).

b) Traditional healers

Traditional healers play a significant role in South African healthcare, including in the field of HIV/AIDS (Moola, 2019: 183). These healers hold great status such that it is considered disrespectful to explicitly question a traditional healer, and this act of respect may also be practised when HCUs consult with western biomedical health professionals (Naidoo, 2014: 425; Penn and Watermeyer, 2018: 29). Reflecting the multiculturalism of South African society and of individuals, HCUs may consult only traditional medicine or only western biomedicine, or they may practise dual consultation by utilising both systems (Penn and Watermeyer, 2018: 29). In cases where HCUs do not adopt a biopsychosocial model of healthcare provision, this may have a negative impact on the consultation as HCPs may not respect HCPs' choices, or HCPs may withhold this information from the HCU so as not to be judged or instructed otherwise.

c) Forms of address

Forms of address hold significant weight in South African communities of practice:

> Black South Africans, especially those of the older generation, typically have two names: *elasemsebenzini*[5] ('name of work', a European sounding first name) and *elasekhaya* or *el'katata* ('name of home', 'name of father', an African first name and surname). In the South African context, use of the 'name of work' is strongly associated with out-group contact, labour exploitation/oppression, and the invisibility of African heritage. (Deumert, 2010: 57)

Socio-linguistic sensitivity in the South African context includes the knowledge that for a person to refer to someone older than them by their first name is considered disrespectful, and using a surname or clan name would be considered respectful (Penn and Watermeyer, 2018: 197). Despite the correct form of address being a sign of respect, as well as appropriate

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[5] This name is today more commonly referred to as *igama lesiNgesi* (English name), whether it is a name from English or Afrikaans. This term also applies both to adults' and children's names, rather than *igama elamsebenzini* (work name) and *igama lesikolo* (school name).

greetings and introductions, these were not recorded in any consultations observed in Deumert's (2010: 57) study. An indirect manner of approaching a problem is considered more polite than quickly and abruptly speaking about it (Crawford, 1999: 35).

IsiHlonipho is the language used by many married amaXhosa women especially in more rural areas, and it makes use of euphemism or substitution to avoid words that refer to or sound like the names of their male inlaws (Crawford, 1999: 33). Because this form of language is seldom used in more urban areas or by the younger generation these women face communication difficulties even when there is an isiXhosa-speaking person available to interpret for them (Crawford, 1999: 33). Within amaXhosa community of practice it is also largely recognised that certain discussions are only appropriate for and among certain genders, for example discussions about circumcision are only seen as appropriate for discussion among men (Cain et al., 2011: 482) and language choice reflects this secrecy (Cain et al., 2011: 480). Women are expected not to acknowledge any sexual feelings, irrespective of their nature or context (Cain et al., 2011: 480).

d) Existentialism and apartheid

The legacy of apartheid affects the power dynamics played out in healthcare settings. HCUs' perceived right to access healthcare in a language they understand can be further explored through the intersection of the impact of apartheid, and the existentialism that may be experienced by people living with HIV/AIDS. Chasi (2014: 12) argues that more attention needs to be given to the impact the historical context of apartheid has on communication on and about HIV/AIDS. This includes questions of existentialism: where democracy should enable people to live their lives to their fullest potential and therefore do not choose to engage in high-risk behaviour, democracy in South Africa has failed in this regard as people's potentials are greatly limited by structural inequality and ongoing oppression, and as a result many people knowingly engage in high-risk behaviours. South Africa's history of apartheid paired with its high rates of HIV/AIDS creates a complex psycho-social setting:

> The damage inflicted by apartheid is such that it is today very difficult for South Africans to look upon themselves, upon their bodies, upon HIV/AIDS, in ways that congruently account for the complex and often traumatic history of colonialism and apartheid (Fassin, 2007 in Chasi, 2014: 16)

Apartheid enforced social positions which intentionally made people feel as though they do not deserve the goodwill and good deeds of others, meaning that historically disadvantaged South Africans may be averse to listening to resourced people who try to help, assist or support them (Chasi, 2014: 22). People who do not have adequate resources may intentionally deny their poverty in an effort to avoid degradation and humiliation, and in so doing also deny the goodwill of others (Lötter in Chasi, 2014: 22). People in these positions may also see acts of generosity from resourced people as a show of unearned privilege and therefore criticise or outright reject it (Chasi, 2014: 22). This lack of epistemic trust may be visible in the healthcare field where doctors, who are perceived as resourced, try to help historically disadvantaged HCUs. Historically disadvantaged and under-resourced people may see listening to those with resources as granting credibility to actions they view as hypocritical (Chasi, 2014: 23). And in some cases where people have experienced an inordinate amount of suffering under apartheid and resultant post-apartheid inequality together with persistent illness, people may feel and act helpless (Chasi, 2014: 16). It is important that when we consider people's behaviours and attitudes towards HIV/AIDS we recognise that a large number of South Africans affected by HIV/AIDS, and by extension TB, are "located at social margins on account of unchosen factors associated with their sexuality, gender, race" (Chasi, 2014: 17), and are at higher risk of experiencing ego depletion (Chasi, 2014: 18).

e) Biomedicine and HIV/AIDS and TB

Diseases such as HIV/AIDS and TB appear to necessitate HCU care that is seemingly not HCU-centred in terms of the HCU's self-efficacy and agency to participate in shared decision-making because of the imperative for HCUs to take the exact medicine regimen exactly as prescribed (Penn and Watermeyer, 2018: 318). In terms of communication with pharmacists this can result in instructive and sometimes paternalistic instructions and explanations from the pharmacists (Penn and Watermeyer, 2018: 318). A return to patient-centred healthcare arises when pharmacists communicate clearly and involve the HCUs in the discussion, as HCUs are then empowered through the knowledge they gain in this way to be in control of their health and treatment plan (Watermeyer and Penn, 2009: 211).

f) The Western biomedical model vs a patient-centred psycho-social model

One problem that persists in South African public healthcare is that the system "adheres to the conventional biomedical health care perspective where treatment is controlled by the health care professional only" (Moola, 2019: 176). A biomedical approach in healthcare provision focuses on illness (Moola, 2019: 174) rather than on the person who is ill. This approach prioritises the authority of the HCP as the ultimate holder of knowledge, information, and decision-making abilities, while ignoring the knowledge and agency of the HCU (Moola, 2019: 174). This framework fitted hand-in-hand with apartheid-style healthcare provision, placing HCPs in an unchallenged position of power over consultations, treatment, and the health of the HCU (Moola, 2019: 180).

On the other hand, a biopsychosocial approach facilitates patient-centred care where HCPs and HCUs can communicate together about treatment and lifestyle. This model recognises the importance of scientific diagnoses, but adds to this a conscious recognition of the HCU, their social context, and the role of the HCP being one – but not the only nor the dictatorial – element in their treatment and healthcare (Moola, 2019: 175). While this better reflects the model of healthcare provision endorsed by the National Health Plan, "the country still has a long way to go before individual patient-centred care can be achieved equally for all South Africans" (Moola, 2019: 171). The National Health Plan (African National Congress, 1994) affirms the intention for HCUs to be informed and involved in decision-making, and to be enabled to care for themselves, particularly in cases of chronic illness. These undoubtedly important elements of healthcare provision beg the question: if a HCU is presented with the relevant information, is that a sufficient condition for them to be informed? And how can a HCU be involved in their decision-making through a language they do not understand? Within the biomedical paradigm the HCU "has no voice" (Moola, 2019: 174), and thus language and communication barriers can be more easily ignored. However, when patient-centred care is actively being promoted, insufficient attention to language and communication barriers are wilful ignorance. Clearly, the HCU's understanding of their condition and treatment, and the steps taken to facilitate this understanding and inclusion, are of equal importance for the desired outcome of informed healthcare. It is therefore imperative that any meaningful steps towards a patient-centred, biopsychosocial healthcare model are cognizant of communication and language barriers and active in the reduction thereof. This is addressed in Chapter 6, where resources and training are explored in more detail.

2.3. Health communication

This section looks specifically at the intersections of communication and healthcare in the South African context, focusing where possible on HIV/AIDS and TB. Studies exploring the communication barriers faced by HCPs and HCUs in South Africa are described, and the effects of these barriers are elucidated, including the role of language and communication barriers in reinforcing power dynamics and the clinical gaze, and the problems this raises for adherence and disease management. Strategies to support health communication are detailed, giving examples from studies in which pharmacists used props, and noting the importance of cultural relevance in communication aides. The complexities of terminology are explored, considering different attitudes towards the use and development of healthcare-specific terminology and the role played by language prestige in a context already fraught with power dynamics. Finally, the common practice of including interpreters in healthcare consultations is explained, illustrating how and why interpreters make up such a large part of healthcare communication in South Africa. The health communication literature included here is used as a basis to inform the needs analysis presented in Chapter 5, and the development of the resources and training as detailed in Chapter 6.

2.3.1. Barriers to communication

a) *Differences in L1 and language proficiencies between HCUs and HCPs*

Language barriers compromise access to healthcare for a large portion of South Africa's population (Naidoo, 2014: 425). In South Africa health professionals and HCUs often do not share a common language, with English and, to a lesser extent Afrikaans, being the languages used most commonly by health professionals in formal settings (Watermeyer and Penn, 2009: 192). These languages are usually second languages or simply not spoken by the majority of HCUs using public healthcare in South Africa (Watermeyer and Penn, 2009: 192), with only 5% of doctors being able to conduct consultations in the HCU's home language at some healthcare sites (Schwartz in Penn and Watermeyer, 2018: 174). This is not to say that communication has been ignored, but on the contrary, "Communication has been identified as the single biggest barrier to health care in a global world" (Penn and Watermeyer, 2018: 3).

b) *HCU's understanding of their condition*

The use of a language in which a HCU is not proficient results in the HCU not fully understanding their condition (Deumert, 2010: 58; Schlemmer and Mash, 2006: 1086). In communication between healthcare practitioners and HCUs with chronic diseases, it has been observed that the amount of information exchanged, the relationship between the healthcare practitioner and the HCU, and the amount of control the HCU has over the conversation can all be linked to HCU outcomes (Naidoo, 2014: 425). Naturally the language competence of both the healthcare practitioner and the HCU allow or limit these types of communication (Naidoo, 2014: 425). Communication is therefore of particular relevance for diseases such as HIV/AIDS and TB, as the quality of healthcare received greatly depends on the HCU and the healthcare practitioner understanding each other (Anthonissen and Sobane, 2013: 264). For HCUs who wish to learn more about and better understand their conditions, this learning typically takes place in communication with other HCUs in healthcare centres' waiting rooms, "creating 'alternative' or 'folk' medical worlds which are expressed in indigenous languages" (Deumert, 2010: 58).

c) Short and simple messaging

Short and simple messages on healthcare are more effective and are generally preferred, irrespective of people's level of education (Doak et al. and National Work Group on Literacy and Health in Dowse, 2009: 156). Healthcare practitioners often experience difficulties communicating HIV/AIDS-related information to caregivers due to the complex concepts, large amounts of information, and the HCU's educational background and understanding of the concepts of the disease (Penn and Watermeyer, 2018: 211).

d) Communication in patient-centred care

In any discussion about 'patient-centred care', the HCU's ability to actively participate in their own care needs to be considered (Naidoo, 2014: 425). In order for a HCU to have any level of autonomy and to be involved in decision-making there needs to be clear communication between the healthcare practitioner and the HCU (Naidoo, 2014: 425).
The importance of context, both of the situation and the people themselves, cannot be understated. In cases where HCUs' daily lives pose significant challenges, it is important that any communication about the HCU's health also takes into account how the HCU sees their situation, in order for the information to not be discarded as irrelevant (Chasi, 2014: 21).
Communication barriers can include more elements than language proficiency: physiologically a communication barrier may arise from factors affecting someone's body such as pain or hunger; psychological barriers may include different individual or culturally-embedded understandings and ways of communicating; and semantically there may be communication barriers that are not mutually understood, even when the conversation participants speak the same language (Wood in Moyo and Salawu, 2017: 102). Non-verbal communication is of significant importance, especially in cross-cultural and cross-linguistic interactions, and yet this type of communication is often not included in health

communication studies (Watermeyer and Penn, 2009: 197). The importance of the inclusion of these elements is highlighted by research demonstrating that both verbal and non-verbal communication can be changed and improved through training that is appropriate for and specific to the health professionals' context (Watermeyer and Penn, 2009: 193).

e) Clinical gaze

Penn and Watermeyer (2018: 212) recommend analysing both the verbal and non-verbal content of interactions in health communication. Chasi (2014: 8) urges that any communication on HIV/AIDS should not only involve cultural and contextual sensitivity, but that those engaged in this communication should be aware that any discussion around HIV/AIDS also raises existential questions in people. HCUs can become disempowered through language barriers, and this disempowerment is framed within a larger discourse of power dynamics within biomedicine, within which HCUs are situated to hold less power than healthcare practitioners (Crawford, 1999: 29). When health professionals cannot communicate with their HCUs, the clinical gaze is limited to uncover and examine only the physically apparent symptoms, whilst also objectifying the HCU rather than allowing for the HCU's agency over their body and their health to be recognised (Deumert, 2010: 57). The use of deictic communication, that is, illustrating symptoms or pointing to a body part, is commonplace in such contexts, elicited by the healthcare practitioner, the interpreter or the HCU themselves (Anthonissen and Sobane, 2013: 270-271), and further feeds into a limited clinical gaze. This is insufficient in cases where a HCU's symptoms, disease or treatment require more complex explanations, such as when medication and treatment need to be explained and when HCUs have psycho-social concerns, which are to be expected in HIV-related treatment (Anthonissen and Sobane, 2013: 271).

f) Adherence and disease management

HCUs' adherence and non-adherence to medication is based on many factors which are difficult to determine and even more difficult to effect and manage (Penn and Watermeyer, 2018: 231). The trauma and fear associated with not being able to communicate, especially in an environment where power dynamics favour the healthcare professional over the HCU, can lead to increased avoidance behaviour among HCUs who experience language barriers in healthcare (Naidoo, 2014: 425). Even without these psychological effects, poor communication and communication barriers can lead to HCUs' non-adherence (Watermeyer and Penn, 2009: 191). In cases of miscommunication and misunderstandings between healthcare practitioners and HCUs, HCUs may have poor medicines adherence even when they believe they are taking their medicines correctly. Many participants in Penn and Watermeyer's (2018: 237) study were intentional with their medicines adherence and believed they were taking their medicines correctly; however, as they did not have a clear understanding of their diseases and medication regimens, they were in fact taking their medicines incorrectly. Approaches to improving medicines adherence such as pill counts and behaviour modification are often unsuccessful and may well be due to their lack of recognition of the complex role communication plays in medicines adherence (Penn and Watermeyer, 2018: 231). This is especially true in the case of HIV/AIDS: the HIV/AIDS epidemic necessitated a change in the role of health professionals to include HCU counselling and education, and adherence monitoring became even more important (Penn and Watermeyer, 2018: 232). Embedded in this is the need to communicate about dosage instructions, lifestyle changes, and face-threatening and taboo topics such as sexual behaviours (Penn and Watermeyer, 2018: 232). The importance of focusing on medicines adherence for TB treatment is further underscored by South Africa's increasing rates of MDR-TB and XDR-TB (Department of Health, 2015: 16).

g) Diversifying the healthcare field

With higher education becoming more accessible across racial and socioeconomic divides, there will be increasingly more health professionals graduating who speak the same home language as some or most of their HCUs (van der Merwe et al. in Penn and Watermeyer, 2018: 327) While there has been an increase in the number of Black African health professionals in South Africa as a result of post-apartheid educational reform (Thackwell et al. in Penn and Watermeyer, 2018: 175), these health professionals are not exempt from communication frustrations and often experience frustration when their knowledge of indigenous languages results in them being expected to interpret for English-speaking White or Indian health professionals (Oppenheimer and Bayer in Penn and Watermeyer, 2018: 175). Even in cases where the healthcare professional and the HCU share a community of practice that is not English, English is still often the language used in healthcare consultations because of its connection to the medical setting, the entrenched power dynamics, and the materials used in the consultation (Mesthrie in Penn and Watermeyer, 2018: 173–174; Anthonissen and Sobane, 2013: 267). Furthermore, migration has resulted in an increase in HCUs from other African countries, as well as health professionals from Cuba, other African countries, and

Eastern Europe, who cannot speak any indigenous South African languages (Penn and Watermeyer, 2018: 173).

h) 'Invisible' language

When Cuban doctors were brought to South Africa there were concerns that the doctors would not be able to provide adequate healthcare services without being able to speak South African languages (Crawford, 1999: 34) – an ironic concern considering many South African doctors are not able to speak the languages of their South African HCUs. One may also wonder to what extent this concern related to indigenous African languages (which many HCPs do not speak), and to what extent it stemmed from HCUs who speak English – the language of power – and were then made aware of the disadvantage they would experience should their HCP not speak this language. Language is often treated as invisible in the healthcare setting, and it is commonplace for health professionals to not record HCUs' home language, nor check which language the HCU speaks, or if the HCU is comfortable with the language the healthcare professional uses (Deumert, 2010: 57; Moyo and Salawu, 2017: 105). Healthcare practitioners' inability to communicate with HCUs in their home language can lead to feelings of frustration and helplessness, especially because of the awareness that these language gaps limit their ability to provide equal healthcare services to those with whom they can communicate and those with whom they cannot (Deumert, 2010: 55). Language barriers also increase the amount of time and effort needed for a consultation to reach its goals, which can increase health practitioners' frustration while decreasing their levels of empathy (Naidoo, 2014: 425). This in turn can affect job satisfaction and staff morale (Deumert, 2010: 55).

i) d/Deaf experiences of healthcare

In Kritzinger et al.'s (2014: 382) study that examines d/Deaf experiences of communication in the South African healthcare setting, it was found that d/Deaf HCUs did not ask health professionals to explain or repeat themselves because they felt shy or were concerned that in so asking they would appear ignorant or be treated as intellectually inferior. By health professionals not making an effort to communicate with their HCUs, many HCUs felt like the healthcare providers did not respect or acknowledge their intelligence or their wish to be involved in their healthcare and the decision-making around it (Kritzinger et al., 2014: 379). In the high-stakes environment of healthcare, HCUs would fear that miscommunication would have negative consequences, and this fear often led or added to mistrust of the health professionals and the healthcare services (Kritzinger et al., 2014: 379). As a result, most HCU participants in this study often left their healthcare consultation without knowing what the diagnosis was or the reasons for their medication (Kritzinger et al., 2014: 381). HCU participants reported their positive experiences to include instances where medically experienced interpreters were used, where the healthcare practitioners used sign language themselves, and where the healthcare providers made efforts to improve communication (Kritzinger et al., 2014: 379). While my research does not focus explicitly on d/Deaf people and their experiences of healthcare, it is important to remain cognizant of the difficulties faced by d/Deaf people in South Africa in any consideration of language and communication barriers. d/Deaf people have been reported to see health professionals less often (Kritzinger et al., 2014: 379), with reasons including communication difficulties and the lack of interpreters available to them (Tamaskar et al. in Kritzinger et al., 2014: 379).

2.3.2. Health literacy

a) Aims of health literacy

Health promotion aims to enable people to take control of their health and, by extension, their lives (World Health Organization in Mokwena, 2015: 197). Health literacy is a necessary proponent of realising this goal (Mokwena, 2015: 197). Health literacy aims to enable and empower HCUs to make informed decisions about when to seek advice from a healthcare professional, how to find the appropriate person, the ability to explain the problem and reasons for the consultation (Schulz & Nakamoto 2013 in Moyo and Salawu, 2017: 104), and to read and make sense of health information (Mokwena, 2015: 197). In order to take medicines correctly and effectively, before any of the other complex medicines adherence factors are considered, a person needs to have a basic understanding and recall of how to take the medicines (Dowse, 2009: 156).

b) Printed materials

In Anthonissen and Sobane’s (2013: 270) study of HIV clinics in Lesotho they found that HCUs seldom read or referred to the printed materials available and distributed at the clinics. There had been no investigation of what information HCUs needed, and HCUs reported that they had not been asked whether they would like to or were able to read the printed materials available (Anthonissen and Sobane, 2013: 270). In response it was recommended that the funds for creation and distribution of such materials are either reallocated to other aspects of care, or redirected to improve the visual communication in the printed materials (Anthonissen and Sobane, 2013: 270).

As part of a health literacy intervention study, Dowse (2009: 160) collected information about the ARVs constituting Regimen 1a and consolidated this in a written HCU information leaflet, which complied with most of the Department of Health's legal requirements in Regulation 10 (Department of Health in Dowse, 2009: 160). The most challenging information to understand in this leaflet was about the possibility of developing resistance by incorrect medicines adherence, and Dowse (2009: 165) suggests that this information be modified to be more obvious and easier to understand. In this study it was found that around 30% of the isiXhosa-speaking HCU participants preferred to read the HCU information leaflet in English: even though they were literature in isiXhosa they found the English version to be simpler than the isiXhosa translations (Dowse, 2009: 166). In general, however, HCUs preferred to receive information leaflets in isiXhosa (Dowse, 2009: 166). In order to contextualise this, it should be noted that health terminology and access to medication (with the exception of traditional medicine terms) is most often in English, and therefore this is the language through which most HCPs are accustomed to accessing health information. This is explored in more detail in the section on *Terminology development*.

c) How health information is shared

Information about health is shared through a variety of media in Africa: through print, theatre, video, television, radio, poetry, dance, drama, story-telling, rhymes, sayings and other folk media (Dowse, 2009: 155). Access and exposure to education and mass media is unequal in South Africa (Lagerwerf et al., 2009: 3), and print media is the most commonly used means, with the most popular forms of print media being posters, billboards and pamphlets (Dowse, 2009: 156). Printed materials can also serve the purpose of filling communication gaps or clarifying confusion that may arise from communication gaps in healthcare consultations (Anthonissen and Sobane, 2013: 269). In line with oral traditions in South Africa and Africa more broadly, most health and medicine-related communication is verbal (Dowse, 2009: 156). Communication barriers aside, this oral communication is limiting because HCUs may forget half of what they were told in their consultation within five minutes after the consultation ends (Kitching in Dowse, 2009: 156). Supplementary written materials have increased and the HCU information leaflet is the most commonly used means of written health communication (Dowse, 2009: 156). A difficulty in creating written materials in a variety of South African languages is that many medical terms are not directly translated or standardised in these languages, meaning that sometimes single medical terms in English are translated using a – often less specific – description (Dowse, 2009: 168). This could also contribute towards HCUs' perception that leaflets written in their home language of isiXhosa are more difficult to read than the English leaflets.

d) Pharmacists' communication

When looking at HIV/AIDS and TB, it is important to note the role pharmacists play in explaining and discussing HCUs' complex medication regimes. As stated by Watermeyer and Penn (2009: 192), "With the advent of HIV/AIDS, the pharmacists' role has expanded from merely 'dispenser of medicines' to 'educator', 'counsellor' and 'adherence monitor'." ARV clinics often have a pharmacy situated within the clinic, where HCUs visit pharmacists monthly to receive their ARVs and other medication, have their health status reviewed, and have their adherence monitored (Watermeyer and Penn, 2009: 194). During these visits the pharmacists will also present, repeat or explain the dosage instructions for the medication (Watermeyer and Penn, 2009: 194).

e) Props as communication

In a study on pharmacists' communication about ARVs it was found that both pharmacists and HCUs often used props throughout the interactions to illustrate and supplement instructions, to check understanding, and to indicate the end of an interaction (Penn and Watermeyer, 2018: 213). Props are physical items used to aid communication through conveying and reinforcing information, adding realism to the conversation, or making instructions or explanations more explicit (Watermeyer and Penn, 2009: 198). The use of props to complement verbal instructions with non-verbal reinforcement meant that the verbal communication could be simplified, including not needing to use or indeed rely on the difficult names of the medicines (Watermeyer and Penn, 2009: 207). In their study, Watermeyer and Penn (2009: 210) found that HCUs found it easier to demonstrate their understanding of medicine dosage instructions using props rather than verbal explanations with reference to the long names for the medicines. HCUs felt that the use of props improved the communication between them and the pharmacist, and as a result there were high levels of HCU satisfaction and confidence in having understood the instructions of how to take their ARVs (Watermeyer and Penn, 2009: 205). In this study the pharmacists found props to be useful aides to the extent that the need for interpreters was greatly reduced (Watermeyer and Penn, 2009: 207). This does not however mean that the props removed all barriers to communication: the pharmacists considered the cultural barriers to be greater communication barriers than language (Watermeyer and Penn, 2009: 207).

f) Culturally-relevant visual aids

Health professionals are often taught that pictures and drawings can be useful additions to verbal explanations to facilitate understanding and recall, especially in cases where HCUs have low literacy levels (Penn and Watermeyer, 2018: 215-216). In order for these visual aids to be helpful, cultural factors need to be taken into consideration, both in terms of the symbols and icons used and referred to (Penn and Watermeyer, 2018: 216), as well as the appropriacy of the drawing’s complexity relevant to the HCU’s literacy or education levels. While visuals can increase HCUs’ understanding and recall of information about their medicines and diseases, the assumption that visuals can be universally understood needs to be interrogated in order for such visuals to be effective (Dowse, 2009: 157). Visual materials used in health education are generally created by health professionals and graphic designers, who may not share the culture of the target audience nor have insight into their visual literacy skills (Dowse, 2009: 157). This means that even if the objects in the pictures are easily recognisable across different communities of practice, the meaning held by these objects may differ for different people (Dowse, 2009: 157; Lagerwerf et al., 2009: 3). Dowse (2009: 157) suggests addressing this potential miscommunication by involving the target audience throughout the design process and to further test the materials with the target audience before they are publicly disseminated.

2.3.3. Terminology

Terminology is an important element in healthcare communication, both across language barriers and within the same language. As with any jargon specific to its field, healthcare terminology can be the cause of many breakdowns in communication. This section considers existing healthcare terminology (bearing in mind that this may differ across contexts), approaches to terminology development in order to inform resource development, and alternative forms of communication which avoid or explain certain terminology.

a) Language prestige

Languages hold status that is socially and politically shaped. The intentional marginalisation of indigenous South African languages by the apartheid government has far-reaching consequences for the status of these languages (Alberts (2000) in Sibula, 2007: 399). A common trope is that terminology, or the lack thereof, is an obstacle to the use or inclusion of African languages in official, academic or scientific domains. Bamgbose and Webb (in Antia and Ianna, 2016: 63) have clearly dismissed this idea as "scarecrow tactics employed to justify inertia or the status quo". In cases where this trope centres around the absence of terminology, it is possible that this concern stems from a misunderstanding that terminology development depends on the creation of new terms, without knowing or acknowledging the role of reinterpreting existing forms (Antia and Ianna, 2016: 71).

b) Healthcare-specific terminology

English terms are often used for symptoms, therapeutic terms and diagnostic procedures, usually because there is no direct equivalent in the African language being spoken (Penn and Watermeyer, 2018: 210), or because the English term has become more standardised than the African language equivalent. These terms include "*TB, HIV, rash, pregnant, prick, mask, scan, positive (meaning HIV positive), pills* and *treatment*" (Penn and Watermeyer, 2018: 210). Conversely, some terms are specific to African languages and cultures and do not have a direct translation or equivalent in English. Some examples of such terms in isiXhosa include "*ingqele*: the cold-hot theory of disease (pneumonia), *idliso* poisoning via food (TB) and *xakaxa* mucous build-up since birth (asthma)" (Levin in Penn and Watermeyer, 2018: 211). Often the names of common illnesses (including *diabetes, arthritis* and *stomach ulcer*) hold different meanings in different communities of practice, such that the name of an illness could have different meanings to healthcare practitioners than they do to HCUs, which also creates a difficult position for interpreters to navigate (Levin, 2006: 1080).

Vocabulary items relating to uncertainty, risk and imprecision are particularly difficult for interpreters to interpret, and therefore the likelihood for error is higher when this discourse is used (Penn and Watermeyer, 2018: 249-250):

> This has been described as the "discourse of uncertainty" (Sarangi and Clarke 2002) and includes verbs: *think, suggest, guess;* modal auxiliaries: *might, may, could;* nouns: *estimate, percentage, chance;* adjectives: *some, quite, about;* adverbs: *approximately," roughly, perhaps;* and hedging disclaimers: *sort of, as far as I know, I don't know.* (Penn and Watermeyer, 2018: 249–250)

Regarding disease-specific terms that are difficult to explain, Evan (in Penn and Watermeyer, 2019: 109–210) has identified the following terms that are frequently used yet difficult to explain and do not have self-evident meaning:

> *CD4 count*
> *Viral load*
> *First-line treatment*
> *Second line treatment*
> *MDR TB*
> *Percentage calculations to do with dosages* (Penn and Watermeyer, 2018: 210).

This is corroborated by Dowse (2009: 166), who found that in HCU information leaflets about ARVs, HCUs self-reported being unable to understand the terms *viral load, CD4 count* and *antiretroviral therapy*, and other commonly misunderstood words included *resistance, pharmacist,* and *capsules.* Dowse (2009: 168) anticipates that as availability of ARVs has increased in the public health sector, and as HCUs become more familiar with HIV/AIDS, it is likely that HCUs would be increasingly familiar with these words (Dowse, 2009: 168)

Linked to the stigma attached to HIV/AIDS, there are several euphemisms and slurs used to describe the disease, its symptoms, and the people who are infected/affected by HIV/AIDS. People who go for voluntary HIV testing are sometimes referred to as 'Channel Os'; by making reference to the music television channel which is considered risqué, this term infers that those going for testing are promiscuous (Kunda and Tomaselli, 2009: 108). Other terms for HIV/AIDS include 'three words' (Leclerc-Mdlala in Kunda and Tomaselli, 2009: 97), the 'modern disease' (Posel in Kunda and Tomaselli, 2009: 98), '*ilotto'* (the lottery) (Horne in Kunda and Tomaselli, 2009: 98) and 'i-ace' (ace [of cards]) (Kunda and Tomaselli, 2009: 98), with the latter two names reflecting the ideas of risk and chance.

When speaking about HIV/AIDS, health professionals need to pay attention to gender and politeness, which would often be influenced by the gender and age of the healthcare professional and the HCU or audience, their respective status as empowered or disempowered, and whether the conversation is private, in a single-sex group, or in a mixed-sex group (Cain et al., 2011: 486). The healthcare professional also needs to balance politeness and the avoidance of direct anatomical terms with the necessity to communicate clearly and effectively give the HCU sufficient information (Cain et al., 2011: 486). Sometimes HCUs use codeswitching as a means to avoid taboo topics in their home language, especially when the HCU and healthcare practitioner differ in gender (Moyo and Salawu, 2017: 106). This is further complicated because some terms that convey politeness may also reinforce patriarchal ideas of gender (Cain et al., 2011: 486). The following is a recommendation from (Cain et al., 2011: 486) of how health professionals should communicate about HIV prevention within amaXhosa communities of practice:

> For a HIV prevention intervention with Xhosa in Cape Town, it is the authors' recommendation to use *penis* for male genitalia, *vagina* for female genitalia and *sex* for sexual intercourse. When the direct or anatomical terms become too emotionally charge [sic] or deemed vulgar, terms derived from other languages enable the HIV interventionist to move outside the culturally restrictive limits of one's own language by reducing the speaker's emotive cultural connotations. In a context where first-language Xhosa speakers do not have any knowledge of English, the recommendation is to use *ipipi* for male genitalia, *ikuku* for female genitalia and *ukulalana* for sexual intercourse. These terms are direct enough to describe the concepts, and only slightly lower on the politeness scale than the English and Zulu terms. (Cain et al., 2011: 486)

The necessity to communicate clearly may well outweigh the need to use terminology that is perfectly balanced with cultural sensitivity, and in such cases the healthcare professional should be knowledgeable about the terminology they use and the cultural and contextual meanings of the terms (Cain et al., 2011: 486). By listening to the language used around HIV/AIDS and adapting it to a target audience, it is possible to have more effective and meaningful conversation with individuals and with communities (Kunda and Tomaselli, 2009: 93). In line with South Africa's 1994 multilingual language policy the Department of Arts and Culture published technical dictionaries or glossaries for a variety of fields (Alberts, 2010: 610 in Nkomo and Madiba, 2011: 145). These dictionaries/glossaries, which include a multilingual HIV/AIDS glossary, were developed by African language terminologists who are first language speakers of the official South African languages (Nkomo and Madiba, 2011: 145).

c) Terminology development

Terminology is the vocabulary of a specific discipline, or 'terms', which hold meaning specific to that discipline, (Sager, 1990: 19 in Antia and Ianna, 2016: 62). It includes the ways of collecting, describing and presenting the terms, and the theory that explains the relationships between the terms and the concepts they represent (Sager (1996) in Nkomo and Madiba, 2011: 147). Terminology development is therefore the development or extension of words and their meanings in specific domains, either to reflect meanings that previously did not exist within that domain for speakers of that language, or to meet new communication requirements (Antia and Ianna, 2016: 62). A term should display the cognitive dimension, it should be correct at the linguistic level, and the communicate dimension should be considered (Nkomo, 2021, p.c.). Accretion, or the growth of vocabulary, can happen through borrowing words from languages in which the term already exists, or creating new terms from within that specific language (Antia and Ianna, 2016: 63).

Terminology development can occur as a systematic activity where the aim is to develop new terminology, and it can occur as a result of translation: the latter is referred to as "ad hoc terminology management" by Wright and Wright (1997, in Antia and Ianna, 2016: 80). Translation plays a central role in terminology development in South Africa (Madiba, 2004 in Nkomo and Madiba, 2011: 150), and in the case of existing health resources in South Africa the so-called 'ad hoc terminology management approach' is common. Language-related professions are all too often plagued by the Dunning-Kruger effect: there are commonly-held misconceptions that any L1 speaker of a language can easily teach it, or translate, or even develop terminology. Oftentimes someone without a background in linguistics will ask anyone to translate, resulting in an uncoordinated approach (Nkomo, 2021, p.c.) because one cannot simply "pull out a bag of tricks" (Fishman, 1983: 108 in Bassey and Ianna, 2016).

d) Approaches to terminology development

A common approach to terminology development is semantic extension, whereby existing words are used for new concepts by extending or redefining their meanings (Antia and Ianna, 2016: 72). Where semantic extension is used, it is important that terminology resources include definitions that make clear the new meaning(s) attributed to the word (Antia and Ianna, 2016: 72). Language acquisition includes a continuous process of lexical disambiguation as new words are encountered: one is continuously refining meanings ascribed to lexical items and readjusting the boundaries between different lexical items (Sonaiya, 1991 in Antia and Ianna, 2016: 64). In terminology development, one should be conscious of the potential for this natural process to be extended: as new terms are introduced in a discipline, users of the term will also refine their understanding of the term and its boundaries with related terms. In this way terminology development reflects the fluidity of language, as meanings and associations develop and change while language is used. In this sense, Antia and Ianna's (2016: 75) situating of terminology development within the processes of child language acquisition and the philosophy of science could be further refined by situating it within theories of adult second language (L2) acquisition, particularly in contexts where the L2 acquired is used by a majority of L2 speakers of that language. In these contexts especially, vocabulary is used to hold specific meaning while simultaneously developing refined or reconfigured meanings through its use. This also serves as a reminder to avoid prescriptivism within terminology development, such as that of the engineered approach of Wüster's General Theory of Terminology (described in Nkomo and Madiba, 2011: 148), as one can seldom (if ever) control exactly how new terminology is conceptualised and used in natural language settings. The understanding of terminology as situated within natural languages, as espoused by later scholars such as Sager, Temmerman and Cabré, is far better suited to real-world use of language, where meanings of terms are dynamic and where specialised communication occurs between a variety of people, across and between everyone from experts to laypeople (Nkomo and Madiba, 2011: 149).

e) Borrowed terms

Dlodlo (2005: 325 cited in Sibula 2007) and Mphahlele (2001 in Sibula 2007) argue that creating terminology by borrowing from European languages is inappropriate as they do not convey meaning and sound clumsy. This speaks to the importance of the cognitive and communicative elements of terminology development; however, such a blanket exclusion of borrowed words makes for a limited conceptualisation. Throughout different languages borrowed and transliterated terms (where a term that is used in one language is included as it sounds in the target language) become integral parts of a languages vocabulary through natural use of the language, particularly in cases where a transliterated version is easily communicated through the existing phonology and prosody of the language. The argument for or against the exclusion of borrowed terms based on their morphology or the meaning they convey is a complex one. In such cases, it becomes important to weigh up the importance of being able to derive meaning from the word itself against the importance of the communicate aspect and whether or not the borrowed term is already widely used. In some cases a transliteration approach is explicitly preferred. For example, when the faculties of Stellenbosch University were officially named in Afrikaans and isiXhosa, the Faculty of Arts chose the transliterated *ifakhalthi yeAthsi* over the extension of meaning required for the suggested *ifakhalthi yobuGcisa* (Sibula, 2007: 402). However, in some cases a preferred term may not hold the desired meaning. For example, using English back-translations to check terms in several Nigerian local languages, Askira (1994, in Antia and Ianna 2016: 74) found that the preferred term for 'x-ray' translated to "photography of the chest", rather than the other suggested term which translated to (medical) photography. An example relevant to the

COVID-19 pandemic is the use of *i-oksijini* (oxygen) as a preferred term to *umongomoya* (source of air). In cases where a (mis)understanding of a concept results in a term that is inaccurate, yet easily accessible or commonly used, one would need to weigh up the importance of accuracy against the importance of an accessible – or in many cases an already commonly-used – term. Language is constantly evolving, and so terms need to be contemporarily appropriate (Antia and Ianna, 2016: 78). Furthermore, not all language is meant for all people in all contexts: the terms used in public health do not need to be the same as the terms used by medical professionals (Nkomo, 2021: p.c.). This holds true irrespective of the language or languages used. Accurate terminology loses its usefulness and appropriacy if it does not meet the linguistic and communicative needs of those for whom it is intended (Nkomo and Madiba, 2011: 146).

f) Metaphors

Language often reflects people's thoughts and perceptions, and within many African languages metaphors serve as a significant indicator of conceptions of diseases such as HIV/AIDS (Penn and Watermeyer, 2018: 217). Metaphors give insight into the knowledge of and attitudes towards those which they describe, and as such an understanding of local metaphors would be beneficial to any healthcare practitioner wishing to undertake any healthcare intervention (Kunda and Tomaselli, 2009: 96). In some cases metaphors euphemise or replace the terms for a disease, which could possibly increase the fear and stigma of the disease (Penn and Watermeyer, 2018: 217). For example, HIV is referred to as *amagama amathathu* (three words, referring to the three letters of HIV) in isiXhosa to avoid using the name 'HIV'. HIV/AIDS metaphors in South Africa also make regular military references, portraying it as "an invasion that must be fought against" (Sontag in Kunda and Tomaselli, 2009: 95). In neighbouring Zimbabwe, HIV/AIDS is known as *makizi yak u mochari* (keys to the mortuary) (Mawazda in Kunda and Tomaselli, 2009: 96) and sometimes *Jemeza* (sad times awaiting) (Mawazda in Kunda and Tomaselli, 2009: 96). The important role language plays in perpetuating stigma is recognised by the United Nations Development Programme, which through their language policy has recommended a language of peace, rather than war, in descriptions and metaphors for HIV/AIDS (Kunda and Tomaselli, 2009: 98). Linguistic representations, including metaphors, also serve as a means for people to make sense of and cope with the diseases which affect them (Kunda and Tomaselli, 2009: 93).

Metaphors are regularly used for explanations and cultural brokerage by HCUs, interpreters, and healthcare practitioners (Penn and Watermeyer, 2018: 218). This includes metaphors created by individuals as well as those used by a community of practice (Penn and Watermeyer, 2018: 218). In some cases the healthcare practitioner's use of metaphors may further confuse a HCU (Penn and Watermeyer, 2018: 222), while in other cases metaphors can build rapport and give healthcare practitioners, HCUs and interpreters insight into each other's world views and experiences (Penn and Watermeyer, 2018: 224), arguably only when people are open to listening and making an effort to understand them. Penn and Watermeyer (2018: 218) pose the following questions regarding metaphors in intercultural healthcare settings:

> The critical questions appear to be: What are the conditions under which metaphors can be a useful tool in communicating about diseases and explaining some of its complexities, and at what point can they serve as a potential barrier to care and adherence (especially in chronic diseases)? What is the role of context (both cultural and verbal) in shaping the appearance and use of metaphors? (Penn and Watermeyer, 2018: 218)

Metaphors may also be used to euphemise discourse, especially when referring to HIV/AIDS (Penn and Watermeyer, 2018: 222). Metaphors relating to HIV/AIDS and TB include the following:

> *the disease we are unable to hold by hand (HIV)*
> *a disease from long ago (HIV)*
> *there's a gogga [bug] in your blood (HIV)*
> *a cocktail; a twin with HIV (HIV and TB)*
> *this one is running too fast [sleeping around] (HIV)*
> *babies are born chilli [with sexual maturity] (HIV)*
> ...
> *the lungs are being eaten (TB)*
> ...
> *I do not eat a sweet with its wrapper on [wear a condom]*
> …
> 'Battle' metaphors were common too:
> *The CD4 is the* **soldiers** *in your body who can fight against any infection (HIV)*
> *The first time I knew about my status I thought this thing is the* **enemy** *(HIV)*
> *We can* **beat** *this TB cancer (TB)*
> *If you don't eat TB it's going to* **fight** *you and then it is going to* **dominate** *your body (TB)* (Penn and Watermeyer, 2018: 218–219)

2.3.4. Interpreting

a) The role of interpreting

Many clinics cater to large numbers of people and suffer from insufficient clinic resources including shortages of medication, staff members being overloaded, staff shortages, and long waiting times (Bodibe in Watermeyer and Penn, 2009: 194; Kritzinger et al., 2014: 380). This often results in healthcare practitioners being rushed in consultations, which has clear effects on interpreting services (Kilian et al., 2014: 163). Health professionals, both in South Africa and globally, are often pressed for time and thus believe checking HCU understanding to be too time-consuming to do regularly (Crawford and Brown in Penn and Watermeyer, 2018: 236). Many healthcare sites have counsellors trained by Non-Governmental Organisations (NGOs) whose role involves assisting the medical team with tasks at the clinic (Penn and Watermeyer, 2018: 179). Unfortunately the role of these counsellors is often not clearly defined and there is less efficiency than hoped for (Rohleder and Swartz in Penn and Watermeyer, 2018: 179). In pharmacy consultations observed by Penn and Watermeyer (2018: 236), it was found that even though the consultations were relatively longer (typically almost 10 minutes each), the time spent checking HCU understanding consisted of a relatively small portion of the interaction, and they thus argue for the expediency of checking HCU understanding to assist with correct medicines adherence.

b) Styles of interpreting

Conduit style interpreting may be used at certain times to achieve specific outcomes, for example to reinforce a statement that has been made that the interpreter views as important or ambiguous and wishes for the HCU or healthcare practitioner to hear it exactly as it was said (Penn and Watermeyer, 2018: 184). A more typical style of interpreting is delayed style interpreting, where the interpreter synthesises and interprets larger chunks of information (Penn and Watermeyer, 2018: 183). In the South African context Penn and Watermeyer (2018: 92) argue that a model of cultural brokerage is more appropriate, where an interpreter assists in making both the language and culture of the HCU and healthcare practitioner understood by one another. The conduit model of interpreting involves the interpreter acting as a neutral agent to transfer information verbatim (Penn and Watermeyer, 2018: 198), speaking in the first person (Penn and Watermeyer, 2018: 182). The use of the conduit approach, and specifically the use of the first person in interpreted utterances, is of greater importance in mental healthcare, as this gives information about the HCU’s insight into their condition and self-awareness (Kilian et al., 2014: 162). Outside of mental healthcare, this model of interpreting is not appropriate in the South African context, especially as the interpreter often also plays the role of cultural broker and needs to interpret both semantic and cultural meaning from the healthcare practitioner and the HCU to be appropriately understood by one another (Penn and Watermeyer, 2018: 198; Schlemmer and Mash, 2006: 1087). Penn and Watermeyer (2018: 317) further argue against using a conduit style of interpreting in South Africa's healthcare setting, reasoning that an 'anti-conduit' style is more patient-centred as it allows the HCU to decide whether or not they need an interpreter and empowers HCUs to take charge of how interpreting and communication takes place. In order for this style of interpreting to be successful the healthcare practitioner needs to relinquish some of their power and control of the communication (Penn and Watermeyer, 2018: 317). Uninterpreted asides, that is, information exchanged between the interpreter and only one party, may assist in making the HCU feel more comfortable, or to build better rapport between the interpreter and the HCU (Penn and Watermeyer, 2018: 185). Quotatives are often used to indicate reported speech, for example "*"the doctor is asking"* or "*the doctor says""* (Penn and Watermeyer, 2018: 190). This is very different to conduit style interpreting, as it marks the different roles and perspectives of the interpreter and those for whom they are interpreting (Penn and Watermeyer, 2018: 190). Interpreters who are formally trained may have less flexibility in their approach and may also have limited local knowledge when compared to informal interpreters (Penn and Watermeyer, 2018: 200). Penn also considers that the overly relaxed approach and manner of a cultural broker or informal interpreter may be non-threatening and reassuring for the HCU, urging that people look beyond traditional ideas of what these roles should look like and instead consider the effects such interactions have on communication (Penn and Watermeyer, 2018: 315).

c) Informal interpreters

Most healthcare centres rely on ad hoc interpreting by informal interpreters (Penn and Watermeyer, 2018: 176). Interpreting is often only sought as a last resort, when healthcare practitioners and HCUs are completely unable to communicate with each other (Deumert, 2010: 59). Informal interpreters may include nurses and other healthcare centre staff such as cleaners and security guards, family members of the HCU, including their children, and other HCUs (Anthonissen and Sobane, 2013: 268; Crawford, 1999: 29; Deumert, 2010: 58–59; Kilian et al., 2014: 160). Being able to speak the same language as someone does not give one an automatic ability to interpret in the medical setting or to convey difficult messages (Crawford, 1999: 37; Schlemmer and Mash, 2006: 1085). In most of these cases the informal interpreter has no background in healthcare or medical terminology (Anthonissen and Sobane, 2013: 269), yet they face the challenge of making the medical world accessible to laypeople (Deumert, 2010: 59). The role of the informal interpreter is often unclear or undefined, resulting in a mismatch between how the interpreter, HCU and healthcare practitioner view and treat the role (Penn and Watermeyer, 2018: 176). Interpreters are typically untrained, and health professionals are also not trained in how to work with an interpreter effectively (Crawford, 1999: 30). This also means that often the HCU's voice is lost (Crawford, 1999: 30). Interpreting is often under-acknowledged and perceived as simply reproducing the same message in another language (Crawford, 1999: 35). However, literal translation is insufficient and inappropriate in the healthcare context, particularly in cross-cultural interactions or when providing healthcare to vulnerable communities (Anthonissen and Sobane, 2013: 263). Informal interpreters are most effective when they have cultural awareness and linguistic competence in both the HCU's and health practitioner's languages (Fatahi et al. in Anthonissen and Sobane, 2013: 268). Interpreters and interpreting services have a significant influence on HCU satisfaction (Schlemmer and Mash, 2006: 1085), HCUs' medicines adherence, the accuracy of diagnoses and the overall medical interaction (Weiner and Rivera in Anthonissen and Sobane, 2013: 268; Jacobs et al. in Deumert, 2010: 59; Penn and Watermeyer, 2018: 178), and people who are effective informal interpreters are often repeatedly called on to assist (Anthonissen and Sobane, 2013: 268).

The potential limitation of informal interpreting is that practice varies greatly from site to site, case to case and person to person (Penn and Watermeyer, 2018: 198). The quality of informal interpreting varies widely, and poor quality interpretations risk errors in taking a HCU's history, delivering a diagnosis, and educating and informing the HCU (Deumert, 2010: 59). Interpreters' style(s) of interpreting may also be influenced by the setting, the disease, or the topic (Penn and Watermeyer, 2018: 180 & 182). Informal or ad hoc interpreting may and often does result in omissions (when information is not included in an interpretation), additions (when the interpreter adds information that was not said by the party they are interpreting for), substitutions (omitting information and replacing it with an addition), condensations (interpreting a summary of what was said) and distortions (changing the meaning of what was said through the interpretation) (Kilian et al., 2014: 162–163; Penn and Watermeyer, 2018: 179).

d) Professional interpreting

Professional interpreting services are often seen as preferable as a means of overcoming language barriers (Kale and Syed in Anthonissen and Sobane, 2013: 275) and providing cultural brokerage between healthcare practitioners and HCUs (Rosenberg et al. in Anthonissen and Sobane, 2013: 275) and emotional support for HCUs (Hsieh and Hong in Anthonissen and Sobane, 2013: 275). While the efficacy and appropriacy of formal versus informal interpreting is debated in a global context, this debate is more academic than pragmatic in the South African context where there are seldom any options other than informal interpreting (Deumert, 2010: 58; Watermeyer and Penn, 2009: 210; Penn and Watermeyer, 2018: 198). While errors made by trained interpreters are typically smaller and less impactful than errors made by informal interpreters, interpreters' accuracy may be determined by their level of training as well as several other factors linked to the interactions within and context of the consultations and the healthcare centre (Penn and Watermeyer, 2018: 180). Interpreting should be considered not only in terms of accuracy, but also in terms of how effective the interpretations and the interpreters are and whether the clinical goals of the session are met (Kilian et al., 2014: 160; Penn and Watermeyer, 2018: 180), similarly indicating a shift away from formal conduit interpreting and towards context-specific and culturally-sensitive interpreting. Where formalised structures do not exist, communication strategies sometimes develop organically with staff and HCUs (Anthonissen and Sobane, 2013: 267). Rather than only focusing on training interpreters, attention should also be given to training healthcare practitioners to work with and effectively use the services of interpreters (Crawford, 1999: 35; Kilian et al., 2014: 163–164).

e) Nurse interpreters

Nurses are preferred to other informal interpreters because of their medical knowledge and familiarity with medical terminology (Anthonissen and Sobane, 2013: 273). Nurses are often resentful of being used as interpreters, except in cases where language services are included in the job description and the nurses are included as part of the team (Penn and Watermeyer, 2018: 177). Even when nurses are not asked to interpret, HCUs often seek help or clarification from nurses after their consultations, as well as sharing more detailed or intimate information with them rather than with the health professionals (Anthonissen and Sobane, 2013: 273). HCUs may also be more likely to direct their anger towards the nurse who shares their language than towards the doctor who holds a position of more power, and similarly nurses were more likely to direct their anger about their invisible role of interpreting towards the HCU rather than the doctor (Crawford, 1999: 39). In cases where other informal interpreters are used there are increased concerns from HCUs and healthcare practitioners about confidentiality, resulting in informal interpreters only being used when absolutely necessary (Penn and Watermeyer, 2018: 177).

Crawford's study (1999: 40) on health communication noted the tensions between English-speaking health professionals and isiXhosa-speaking nurses who were regularly called on for interpreting services. As her study was published only five years into South Africa's democracy, it encapsulates many of the tensions experienced as the South African healthcare system diversified, and now twenty years later it is worth noting that many of these tensions still remain. Crawford noted that many HCUs had to mime their symptoms when there was no isiXhosa-speaking nurse available to interpret (Crawford, 1999: 28), which is further reflected in the works of, for example, Anthonissen and Sobane (2013) and Deumert (2010).

f) *Does interpreting save time?*

In the absence of a formalised system for interpreting, simply looking for an available informal interpreter hinders the efficiency of consultations (Schlemmer and Mash, 2006: 1085). Some healthcare practitioners feel the presence of an interpreter lengthens a consultation, while others feel there is no difference in length between consultations with and without interpreters (Penn and Watermeyer, 2018: 18). In cases where health professionals have no proficiency in the HCU's language the only assessment for the quality of an interpretation is the length of the interpretation in comparison to what was said by the doctor or HCU, and the appropriacy of the response received from the HCU through the interpreter (Deumert, 2010: 59; Schlemmer and Mash, 2006: 1085). A common cause for frustration between doctors and nurses providing interpreting services is the tension from interpreters having longer exchanges than what the doctor had asked, and interpreters feeling pressured to be efficient with time (Crawford, 1999: 30). The interpreter's perceived or real need to save the healthcare practitioner's time means that they may summarise information given by the HCU (Anthonissen and Sobane, 2013: 272; Crawford, 1999: 35). Information is more likely to be omitted by the interpreter when longer utterances are interpreted (Kilian et al., 2014: 163). In so doing the interpreter may inadvertently be making diagnoses on behalf of the healthcare practitioner, as information deemed irrelevant by the interpreter may be important information for the healthcare practitioner, and may be left out of the interpretation (Crawford, 1999: 35).

Informal interpreters are often caught between their desire to advocate for the HCU and their intention to act in accordance with the healthcare centre’s goals and institutional culture (Kilian et al., 2014: 164).

HIV/AIDS & TB in South Africa

As described in the previous chapter, South Africa is in many ways at the forefront of the HIV/AIDS and TB epidemics. In this section some of the key factors influencing HIV/AIDS and TB are discussed, considering how social factors such as the historical context, gender, and stigma contribute to inequalities in healthcare; describing the problems arising in medicines adherence; and noting the impact of COVID-19.

2.3.5. Historical context

The historical context in which the HIV/AIDS epidemic began in South Africa is important to note. As summarised by Moola (2019: 171), “The injustices of the colonial and apartheid systems negatively affected the public health care system in South Africa.” The availability and quality of public healthcare was purposefully and vastly unequal, and these inequalities still pervade the public healthcare system in South Africa today (Moola, 2019: 171). With regard to HIV/AIDS specifically, the racist ideologies entrenched by apartheid paired with racial imbalance of HIV/AIDS affecting mostly Black Africans meant that the HIV/AIDS rhetoric grew from a place where it “claims to be about saving lives, but involves addressing others as though their humanity is not sacred” (Chasi, 2014: 20). The inequalities and divisions of apartheid still remain as part of its legacy, such that the current demographics of those affected by HIV/AIDS are the same groups of people who were oppressed under apartheid, and who are still heavily affected by post-apartheid inequality (Chasi, 2014: 11). The employment and living conditions in the mining industry in South Africa, which included migrant labour and hostel accommodation, played a significant role in the transmission of HIV/AIDS in South and southern Africa (Chasi, 2014: 23). Increased media and public attention has also recently been given to the contribution the mining industry made to South and southern Africa’s TB infection rate, with mining companies being aware of the potential danger for miners to contract TB yet doing very little to prevent this (see for example the documentary *Dying for Gold* (2019)).

2.3.6. Stigma

Stigma is often attached to diseases that are perceived as the infected person's responsibility, and when it is thought that the disease could be avoided through perceived 'responsible' and 'acceptable' behaviour there is an increase in anger towards so-called 'immoral' actions thought to bring the disease, rather than pity or support for the diseased person (Herek in Kunda and Tomaselli, 2009: 97). The stigma surrounding HIV/AIDS is based on the connotation between HIV/AIDS and promiscuity (Kunda and Tomaselli, 2009: 96). This is evidenced in metaphors based on social shame, rather than on knowledge about the disease itself, its transmission and prevention (Kunda and Tomaselli, 2009: 96). People living with HIV/AIDS are stigmatised through other people's visual diagnoses of them (Kunda and Tomaselli, 2009: 105). Due to the 60% comorbidity rate of TB among people living with HIV/AIDS (Department of Health, 2015: 16), TB is often used as a marker or an alternative label for HIV/AIDS (Kunda and Tomaselli, 2009: 107). Stigma, and the experience of sexual shame, often discourages or prevents people from seeking treatment and care (UNAIDS in Kunda and Tomaselli, 2009: 96). This stigma has led to people being ostracised from their communities, and in some cases murdered, in instances of "street justice" intended to punitively reduce the spread of HIV/AIDS (Chasi, 2014: 46).

2.3.7. Gender imbalances

HIV can be spread through different means, primarily intravenous drug use and homosexual and heterosexual sexual intercourse with some means more common in certain countries than others. In Sub-Saharan Africa HIV is spread predominantly through heterosexual sexual intercourse (Chasi, 2014: 28; Kunda and Tomaselli, 2009: 94). Gender inequalities and dynamics within a heterosexual relationship mean that women are more at risk of being in power-imbalanced relationships where they are not able to exercise their agency in HIV risk reduction, for example her authority to request or insist on using a condom may be undermined or she may be implicitly shamed into not using or requesting a condom (Cain et al., 2011: 478; Lagerwerf et al., 2009: 3). Gender inequalities may also be exacerbated by socio-economic status, as women engaged with transactional sex are more often women with lower socio-economic status (UNAIDS in Lagerwerf et al., 2009: 3). Lagerwerf et al. (2009: 2) argue that HIV/AIDS prevention messages need to include the empowerment of women such that they become able to change their positions of vulnerability in sexual relations and negotiations; however, I argue that this places a near-impossible burden on women, unless this communication actively includes men to participate in alleviating the heightened power dynamics in sexual relations.

2.3.8. Medicines adherence

TB rates in South Africa are compounded by poor medicines adherence, which is typically due to inadequate HCU initiation or follow-up, and can result in increased resistance to initial treatment regimens (Department of Health, 2015: 18). In these cases treatment may become more complicated and more expensive, and TB rates of infection may grow (Department of Health, 2015: 18). HCUs' lack of understanding of their disease and its treatment and prevention also hampers the success of TB treatment programmes (Penn and Watermeyer, 2018: 33).

While AIDS is a chronic condition for which there is no cure, it can be managed with ARV medicines. ARV treatment regimens are often very complex (Penn and Watermeyer, 2018: 31), these medicines require strict adherence levels of taking 95% of the prescribed ART, and often have significant side-effects, and without strict adherence could result in resistance and the failure of the therapy (Dowse, 2009: 157; Okonji et al., 2022: 2). Lower levels of adherence can contribute to risks such as morbidity, treatment failure, transmission of the virus to others, and the development of drug resistance (Okonji et al., 2022: 2).

Despite the importance of adherence in ARV therapy, adherence is still low in many cases, and this is due to a number of complex and intertwined factors including "forgetfulness, substance abuse, drug adverse effect, perceived lack of social support, health illiteracy, mental health issues such as depression, self-stigma, […] advanced HIV status" (Okonji et al., 2022: 2); food insecurity (due to gastrointestinal side-effects and the effect of increased hunger when taking ART) (Okonji et al., 2022: 2); and "staff shortages, long waiting times, negative experiences with clinical staff and medication stock outs" (Okonji et al., 2022: 2). When HCUs begin ARV therapy they may be experiencing depleted physical and emotional strength, yet at this time they also receive a lot of important and necessary information which they need to remember in order to adhere to their medicine correctly (Dowse, 2009: 157). These factors during counselling can be exacerbated by the limited availability time in a consultation, and limited availability of healthcare services within a distance accessible for the HCU (Okonji et al., 2022: 2-3).

2.3.9. The impact of COVID-19

Due to the immunocompromising effects of HIV/AIDS and TB, there is the possibility of people living with HIV/AIDS and/or TB being at greater risk of severe COVID-19 (Abdool Karim and Abdool Karim, 2020: 367). While it became apparent that diabetes had a significant effect on COVID-19 mortality, with 52% of COVID-19 deaths having diabetes as a comorbidity, HIV/AIDS and TB comorbidities made up for 12% and 2% of COVID-19 deaths respectively (Abdool Karim and Abdool Karim, 2020: 367) as shown by the public data collected in a study conducted by the Western Cape Provincial Government on the death risk of COVID-19 (Davies, 2020). Furthermore, the lockdowns implemented in response to the COVID-19 pandemic had a notable impact on HIV/AIDS and TB diagnosis, care and treatment. While the number of ART collection visits remained stable, HIV testing decreased by an estimated 47.6%, ART initiations decreased by an estimated 46.2%, and TB PCR testing decreased by an estimated 59% with South Africa's first lockdown in April 2020 (Dorward et al., 2021: e158; Abdool Karim and Abdool Karim, 2020: 366), with the decreases most pronounced in urban areas (Dorward et al., 2021: e163). ART collections decreased in the first month of lockdown, but quickly returned to pre-lockdown levels the following month (Dorward et al., 2021: e164). HIV testing and ART initiations gradually increased over the following three months as the lockdown restrictions were gradually eased (Dorward et al., 2021: e163). TB and COVID-19 are respiratory infections with similar symptoms and the propensity to spread more easily in conditions of poverty where physical distancing is more difficult to implement (Abdool Karim and Abdool Karim, 2020: 367). This meant that community outreach methods of contact tracing and quarantine monitoring already established for South Africa's TB epidemic could be adapted for the COVID-19 pandemic (Abdool Karim and Abdool Karim, 2020: 367). In addition to concerns for personal health during the pandemic (especially due to lack of personal protective equipment and limited capacity for physical distancing in clinics), limited clinic opening times, and increased difficulties to reach clinics (e.g. restrictions on movement and travel), 28 000 HIV community healthcare workers (CHWs) were reassigned to COVID-19 screening (Dorward et al., 2021: e158, Abdool Karim and Abdool Karim, 2020: 367). As CHWs typically share the language and culture of the HCUs with whom they work, it is notable that language and communication barriers that often accompany top-down messaging and external HCPs were likely limited by this localised approach. It is recommended that "After lockdown, and in any future COVID-19 restrictions, strategies to catch up with HIV testing and increase ART initiation should be implemented, alongside efforts to maintain treatment provision"

(Dorward et al., 2021: e159). An important part of this could include integrating existing community engagement and outreach for HIV/AIDS and TB with the COVID-19 response (Abdool Karim and Abdool Karim, 2020: 367), rather than replacing one with another.

2.4. Discussion and conclusions

By presenting information about HIV/AIDS and TB in South Africa and descriptions of existing health communication strategies and training, this chapter has illustrated the severity not only of the HIV/AIDS and TB epidemics but also the important role that health communication plays in ameliorating these epidemics. It is clear that inequalities abound in South Africa in terms of access to and quality of health services, and in terms of the languages used in healthcare consultations and health information. These inequalities reinforce a Western biomedical model rather than a biopsychosocial model, impeding patient-centred care and reinforcing the clinical gaze. This is of particular concern for South Africa's notable burden of HIV/AIDS and TB, because these diseases require HCUs' understanding of their disease and treatment, and comprehensive counselling.

In this chapter the multicultural nature of South African society has not only been considered; the importance of integrating ethnorelative practice to improve health communication has been emphasised. The account of South Africa's history and current socio-political landscape makes it clear that there is a general lack of political will, as impressive policies are consistently not translated into practice. Indeed if HCPs wish to address these challenges themselves they are largely left to informal and ad-hoc arrangements. However, some models of communication, for example the use of props, pictograms, and (in some cases) interpreting can have a positive impact. In this regard, health communication has been explored in detail by identifying barriers to communication and weighing the benefits, weaknesses and challenges of different types of health communication.

This chapter has laid the groundwork to answer research questions 1 and 2 (*How do healthcare providers and healthcare users communicate in HIV/AIDS and TB healthcare consultations when they are not fluent in the same language?* and *What communication resources and training are appropriate for the provision of HIV/AIDS and TB healthcare in South Africa?*). This was done by describing HCPs' communication strategies and some of the resources and training that have been provided to HCPs in South Africa, as described by the literature. This literature is extended to Chapter 5, where two needs analyses are conducted to validate and further investigate how HCPs and HCUs navigate communication barriers. The literature and needs analyses are considered together to inform Chapter 6, where existing resources and training are further detailed (both those described in academic papers and those outside of the academy) and built upon, and finally tested for their feasibility in Chapter 7.

Chapter 3: Theoretical framework of this research project

3.1. Introduction

This research responds to the problem of language and communication barriers in South African healthcare, in particular for the provision of HIV/AIDS and TB. As mentioned in the previous chapters, this theoretical framework is based on how communication between HCUs and HCPs can be improved for better access to healthcare. South Africa is regarded as a country with leading language inclusion policies, and even the National Department of Health has a policy on language services (Department of Health, 2015: 1). The Constitution of South Africa protects the rights of patients as Section 27 (a) states that everyone has a right to access to healthcare services (1996). Despite this, the stated policies are not being implemented at healthcare institutions. As set out in Chapter 1, in order to address this problem, the research aimed to answer the following questions:

1. How do healthcare providers and healthcare users communicate in HIV/AIDS and TB healthcare consultations when they are not fluent in the same language?
2. What communication resources and training are appropriate for the provision of HIV/AIDS and TB healthcare in South Africa?
3. How feasible is it to implement and measure the suggested resources and training?
4. What are the effects of the suggested communication resources and training in healthcare provision?

In order to answer the above questions, the following objectives were set:

1. To identify the main communication problems experienced by healthcare providers and healthcare users.
2. To identify the main communication strategies used by healthcare providers and healthcare users.
3. To create and implement communication resources and training to be used by healthcare professionals in the provision of HIV/AIDS and TB consultations.
4. To analyse the effects of the communication models in terms of feasibility of implementation and satisfaction in a pilot feasibility trial.

This chapter sets out a framework within which these research questions can be interpreted, and provides a theoretical backdrop against which the research objectives and study results can be explored. In this chapter the epistemological and ontological framework of the thesis is clarified; the concepts explored in this research are defined; Hulsman's goal-oriented theory, from within the theoretical school of behavioural change models, is presented; and a goals framework is drawn up to illustrate the links between Hulsman's theory and the objectives of this research.

3.2. Epistemological and ontological framework

This research departs from a constructivist ontology, with an interpretivist epistemology. As this theoretical position naturally brings subjective perspectives, how these perspectives are informed and balanced is explained in this section. A mixed-methods design was employed, using PAR and pilot feasibility trial. This methodology fits into a 'critical theoretic paradigm' (Ernest in Munn-Giddings, 2021: 87). It is concerned not only with 'propositional knowing' (Munn-Giddings, 2021: 87), or the discovery and understanding of knowledge; but also with the search for how social life, interactions and institutions can be improved. This is then explored through 'practical knowing' (Munn-Giddings, 2021: 87), wherein knowledge is created through actively implementing what has been theorised or proposed.

3.3. Definition of concepts

This research focuses on the intersection of **communication** and **healthcare**. In this research project, **healthcare communication** is understood as the communication between HCPs and HCUs – as well as those who assist in their communication – about the HCU's health. **Communication** includes written and oral language, as well as non-verbal communication such as gestures, body language, and illustrative visuals such as props or pictures. **Healthcare professionals** include anyone whose profession entails providing healthcare services: doctors, surgeons, pharmacists, nurses, and so on. **Healthcare users** include people who make use of public or private healthcare services to consult a healthcare professional. This term is synonymous with 'patient', but has been used in this thesis because of the relative agency associated with the term:

> However, the use of this term [patient] may implicitly suggest a passive and hierarchically lower position in relation to the professional, as the origin of the term is from the word "sufferer", derived from the Latin word "patients", from "patior", meaning "to suffer". … A user is anyone who uses or enjoys a collective good related to a public or private service. Therefore, the term "user" seems to be a broader term capable of extending beyond passive and liberal concepts to a place where health is not only perceived as a consumption good regulated by market laws, but also a

> turning point where the concept of healthcare is perceived as a human and social right regulated by citizenship.
> (Saito et al., 2013: 176)

A **communication barrier** occurs when two or more people do not understand each other's intended meaning clearly as a result of different understandings through the medium of communication, for example due to different proficiencies in or interpretations of the language, gesture, jargon, or references used. With reference to health communication, a **language barrier** occurs between HCP and HCU when the communication barrier is the result of different language proficiencies. It is understood as one type of communication barrier, and is not synonymous with a communication barrier.

Language prestige can play a role in language barriers, through the structural creation or perpetuation of language barriers, or through influencing existing interpersonal language barriers. Language prestige is the relative status of a language, linked to perceived or real social, economic or educational power associated with the language. Kamwangamalu (2003: 228) writes of the prestige of English above Setswana in Botswana as a language that "is seen as a powerful economic and educational tool, the language with higher social status and prestige"; similar could be said for the case of English in South Africa, with the impact of language policies during apartheid leaving an additional negative legacy. Indeed, the prestige of English above indigenous African languages in much of sub-Saharan Africa can be understood as described by Bamgbose (1999) below:

> One phenomenon, which is true of practically all countries in Sub-Saharan Africa, is the subordinate status of African languages in relation to the imported European languages. The root of this problem can be traced mainly to colonial language policies.
> (Bamgbose, 1999: 13)

All of the above concepts converge at **health communication resources.** Healthcare and communication resources are both broad categories. The health communication resources discussed in this thesis refer specifically to physical or digital items that can be used to assist with healthcare, and do not include intangible resources such as knowledge and language proficiency, or items required for the operation of a health site such as medical equipment.

3.4. Behavioural change model

3.4.1. Hulsman's goal-oriented theory

The theory used for this research is situated within the school of behavioural change models, adopting Hulsman's (2009) goal-oriented theory. This theory draws, in part, from the Theory of Reasoned Action (Fishbein and Ajzen, 1975) and the Theory of Planned Behaviour (Ajzen, 1985), which explain human behaviour as being goal-directed. Hulsman's theory reflects this in the idea that "all communication is inherently goal-oriented, problem-solving behavior" (Hulsman, 2009: 303). His theory brings together communication research and education with the notions that (a) health communication behaviours should be considered within the context of the goals of a consultation; (b) that communication goals are permanently changing, rather than fixed; and (c) communication abilities rely on perceptual skills in addition to behavioural skills (Hulsman, 2009: 303). In this context, goals are understood to be future conditions that a person aims to achieve or maintain through the actions they take (Hulsman, 2009: 303), and can be subdivided into *primary goals* (the main reason for the interaction, for example, to take a HCU's history) and *secondary goals* (steps taken in order to achieve the primary goals, for example asking questions about a HCU's previous experiences) (Feldman-Stewart, Brundage and Tishelman in Hulsman, 2009: 303).

While communication choices are intentional, they are usually made independently of conscious decision-making (Hulsman, 2009: 305). Through practise, behavioural skills which were consciously acquired often become second nature, where communication behaviours occur as a result of learnt and practised or repeated skills or actions (Hulsman, 2009: 305). Research question 1 (*How do healthcare providers and healthcare users communicate in HIV/AIDS and TB healthcare consultations when they are not fluent in the same language?*) can therefore be viewed through a lens of intentional, conscious or unconscious communication behaviours.

Hulsman (2009) refers to these unconscious communication schemata as *scripts*, which "arise from repeated experiences with real world events [and] enable us to quickly interpret complex events with a certain situation and to make predictions about how these situations will develop." (Hulsman, 2009: 305). The communication resources and training proposed by this research therefore attempt to tap into these scripts, with the intention of facilitating the acquisition of new scripts which can be used in various situations where HCUs and HCPs encounter communication barriers as a result of language barriers. Therefore, research question 4 (*What are the effects of the suggested communication resources and training in healthcare provision?*) can be considered – in part – as an assessment of the successful impart and uptake of new cognitive scripts.

Of particular relevance to this research is the context-specificness and responsiveness to change of Hulsman's theory. This informs research question 2 (*What communication resources and training are appropriate for the provision of HIV/AIDS and TB healthcare in South Africa?*) through a heightened awareness of context and changing circumstances in health communication interactions.

3.4.2. Goals framework

The goals framework (Figure 4) used in this thesis draws from literature to hypothesise the links between the intervention and factors that could lead to the primary goal of a decreased HIV/AIDS and TB disease burden in South Africa. Although the focus of this framework is on communication, it does not purport to explain the effect of this communication intervention as the only factor contributing to a decreased burden of HIV/AIDS and TB in South Africa. Rather, it describes the knock-on effect that improved communication could have, as part of a holistic approach to HIV/AIDS and TB healthcare – in the way that action-oriented secondary goals can facilitate the achievement of the overall primary goal(s) (Hulsman, 2009: 303). In both the needs analyses and the pilot feasibility trial we did not access healthcare users' (HCUs') data, and therefore could not measure, for example, adherence or improved disease outcomes. The number of healthcare professional (HCP) participants in the pilot feasibility trial did not allow for us to detect small effect size changes, and therefore to link this study to concrete findings on adherence and health practices would have had limited, if any, validity. Therefore, this goals framework situates what was measured in the pilot feasibility trial (which was informed by the needs analyses) among findings from related studies, and in this way logically builds links between variables and outcomes.

The goals framework reasons that if healthcare professionals are provided with the appropriate resources and training, communication between HCPs and HCUs improves. With improved communication, it is possible for HCUs to gain better understandings of their disease(s), and for HCUs to have greater trust in the treatment and advice they receive from their HCPs. HCUs' increased understanding of their disease(s) and trust in the treatment and advice they receive can in turn have a positive effect on their medicines adherence and good health practices. By facilitating the reduced spread of HIV and TB, and by increasing people's prospects for HIV viral loads to be managed and for TB to be cured, adherence and good health practices play a key role in reducing the burden of HIV/AIDS and TB in South Africa.

It should be noted that even though a decreased HIV/AIDS and TB disease burden is the final variable and here explained as the primary goal, it is not the singular goal of the pilot feasibility trial, as there is value inherent in each secondary goal too (for example, increased HCU understanding of their disease is valuable for HCUs to have increased agency in their health). Naturally, there are numerous other factors that could contribute to each part of this framework that are not included here, for example HCUs' beliefs around medicines and disease, the positionalities of the HCPs and HCUs, and other elements of the healthcare experience. Some of these are noted in the framework (in grey font), but are not discussed in detail here.

The goals framework depicts observed variables (items that were measured) from the questionnaires in rectangles, and latent variables (what was not measured in the pilot feasibility trial) from the literature in circles. The literature on which this goals framework is based focuses primarily on HIV/AIDS and/or TB in South or southern Africa. However, the use of ARTs in Global South countries is relatively limited (despite South Africa's large-scale roll-out) and therefore research on barriers to adherence – particularly qualitative research – is also limited (Dahab et al., 2008: 2). In some instances, literature focused on the Global North has been used, and in these cases this has been noted and contextualised.

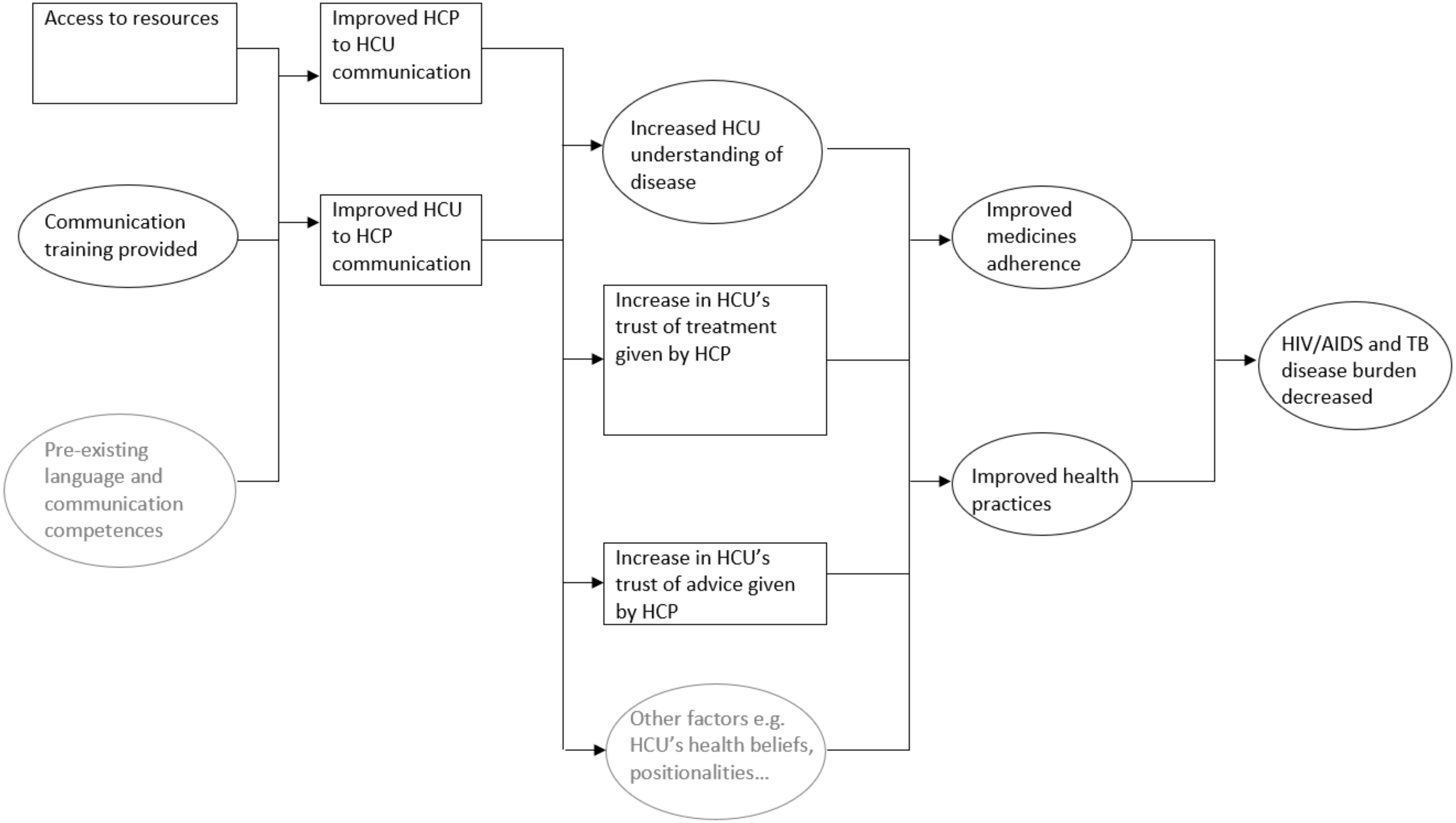


Figure 3: Goals framework

Resources and training → Improved communication

Access to resources was measured in the pilot feasibility trial in terms of how many HCPs received the resources, and how many did not (the intervention and control groups). While some communication training was provided by this intervention, the training took the form of a self-study manual without any formalised training sessions. This is insufficient to include 'communication training provided' as an observed variable. In the case of nurses in South Africa, there is limited training for HCP-HCU communication due to the generally prescriptive nature of clinical care (Medina-Marino et al., 2020: 2). In South Africa HCUs will usually not see the same nurse at their subsequent clinic visits, which limits the ability for nurses to build a stronger relationship with HCUs (Medina-Marino et al., 2020: 2). These factors together impede HCUs' opportunities for increased health literacy and to develop good communication with their HCPs (Medina-Marino et al., 2020: 2).

Improved communication → Increased understanding and increased trust

Communication between HCPs and HCUs can have a direct impact on HCUs' outcomes (Medina-Marino et al., 2020: 2). HCUs' health literacy can also have a direct impact on HCUs' outcomes (Medina-Marino et al., 2020: 2). While this goes hand in hand with communication, good communication between HCPs and HCUs can have a positive impact on HCUs' health literacy.

A healthcare user receiving treatment for sexually transmitted infections (STIs) in the study by Medina-Marino et al. (2020) illustrated the impact of good communication on her relationship with the HCP:

> She spoke to me like… what can I say, like a friend. We were like speaking as [if we were] having a friendly conversation … A person speaking to you friendly, openly. You asking questions, or [them] asking you do you have any questions. It makes … me feel relieved ….
> (Medina-Marino et al., 2020: 4).

Improved communication between HCPs and HCUs – particularly with regard to language – has been found to have a relationship with improved adherence (Dahab et al., 2008: 4). Counselling from HCPs can help HCUs understand the role of adherence in curing or curbing their disease or virus (Medina-Marino et al., 2020: 4).

Communication and understanding do not necessitate HCUs' trust in medication. General hesitancy to take medication and uncertainty of the treatment can heavily affect HCUs' trust in medication. In such cases, this mistrust may dissipate when HCUs have first-hand experience of the medication working, for example:

> [On the] first day, I was like, 'Are they crazy? Should I drink all these tablets? Are they insane? How am I going to do it?' … because they gave me like … two [pills] of each the first time [for STI treatment] and then just one of the ARV's, [and] so I was like, 'How am I going to drink all these pills at once?'. Because I wasn't drinking any pills before. So now … everything has to change. I need to get used to drinking them, and some even has a smell. And then, sometimes you feel nausea [after taking the pills]; you want to vomit … (28-year old with CT & NG).
> (Medina-Marino et al., 2020: 5).

Increased HCU understanding, *HCU trust in treatment*, and *HCU trust in advice* are described separately in the goals framework because, even though there is a link between these three items and there is certainly the potential for them to influence each other, particularly for increased HCU understanding to have a positive effect on HCU trust in treatment and HCU trust in advice, one does not necessitate the other. In Medina-Marino et al.'s study (2020), it was found that while a positive relationship between the HCP and HCU increased HCUs' trust in the HCP, it simultaneously increased HCUs' reliance on the HCP for information and a decrease in HCU's perceived need to understand and take ownership of their diagnoses and treatments (Medina-Marino et al., 2020: 6). Therefore, all three of these elements combined are most likely to have a positive effect on HCUs' medicines adherence and good disease management practices.

Increased understanding and trust → Improved adherence and health practices

Some of the factors associated with low ART adherence are structural barriers (e.g. high cost, unavailability of ARVs), individual factors (e.g. self-efficacy, anxiety), a lack of support (e.g. social support, family support), negative perceptions of the effects of ART, and fear of HIV status being disclosed and being subjected to associated stigma and/or discrimination (Dahab et al., 2008: 2). While there is not a consistent association between lower education levels and poor adherence, in Dahab et al.'s study (2008: 4) HCPs believed there was a strong relationship between lower levels of education, but HCUs did not. This is possibly because lower education levels have been conflated with a more complex web of structural problems and barriers, which also affect access to and completion of education. People with structurally impeded access to education are likely to also experience other factors such as greater structural barriers and lack of social support. Additionally, in the case of South Africa, low education levels could also indicate greater language barriers between HCUs and HCPs in cases where the HCP does not speak the local language, which in turn can have an impact on adherence (Dahab et al., 2008: 4).

Dahab et al. (2008: 4) found a negative relationship between the use of traditional medicine and ART, which was due to conflicting advice given by traditional healers and clinic staff. This could be viewed as one element of the role of HCUs' trust in their HCP: in cases where HCUs do not trust their HCP, or when they trust the clinic staff less than traditional healers, it is possible that ART adherence could be impeded.

Medina-Marino et al. (2020) conducted a study of women living with HIV who were receiving treatment for STIs. While their study did not look at the role of trust and health literacy in HIV/AIDS and TB specifically, and the sample was specifically pregnant women and therefore not a wholly representative sample, findings from this research can be cautiously applied to people seeking treatment for HIV/AIDS and/or TB in South Africa when looking specifically at trust and health literacy. Especially as people – and women in particular – are often subjected to stigmatisation, including by HCPs, because of the risky sexual behaviour that is associated with contracting STIs and HIV (Medina-Marino et al., 2020: 6). Further to this, certain elements can be strongly linked between STI and HIV/AIDS and TB counselling, for example the fear or anxiety of speaking about the diagnosis with a partner. It was found that HCUs' anxiety about disclosing their diagnosis to their partners was lessened as a result of supportive counselling they received from nurses who had received communication training in the study (Medina-Marino et al., 2020: 4–5). This supportive counselling also had a positive impact on reducing HCU's fear about their STI diagnosis (Medina-Marino et al., 2020: 4–5). In turn, this meant that HCUs were better equipped to follow good health practices, including disclosing their status to their partners, and completing their treatment (Medina-Marino et al., 2020: 6). It should also be noted that the HCPs included in Medina-Marino et al.'s (2020) study were nurses, while the present study includes all HCPs, which may also include different power dynamics, interpersonal dynamics, inter-cultural dynamics, and as such different trust dynamics.

On the other hand, HCU's increased trust in their HCP can in some cases have an inverse relationship with increased understanding. For example, in Medina-Marino's (2020) study, it was found that HCUs' increased trust in their HCPs allowed for a reliance on HCPs to take charge of the health of the HCU, rather than prompting the HCU to take increased ownership of their health knowledge and decisions (Medina-Marino et al., 2020: 7).

Improved adherence and health practices → Lower HIV/AIDS and TB burden

Close adherence to ART plays an important role in the suppression of viral loads, in reducing the progression of the disease, and in the survival of people living with HIV/AIDS (Dahab et al., 2008: 2).

3.5. Discussion and conclusions

This chapter clarified the constructivist ontology and interpretivist epistemology as the theoretical foundation of this research. The concepts around communication and healthcare and the intersection thereof were expanded on. Hulsman's goal-oriented theory was then presented and tied to this research, in particular through its application to the research questions. The behavioural change perspective of Hulsman's goal-oriented theory can be seen as challenging traditional theories as it emphasises the fluid and dynamic nature of communication within the healthcare context, rather than viewing it as rigid and fixed.

The transdisciplinary nature of this research, paired with a mixed methods approach, allows for a holistic exploration of the problem of healthcare communication in South Africa, and for exploring possible practical solutions. Through the implementation of this theoretical framework, this research extends on existing knowledge by (a) applying Hulsman's goal-oriented theory to the specific context of HIV/AIDS and TB healthcare communication in South Africa; (b) considers communication and trust as integral secondary goals in healthcare consultations; and (c) delving deeper into the practical realities of the implementation gap between language in healthcare policy and practice. The focus on HIV/AIDS and TB communication, paired with the PAR approach, illustrates how goal-oriented theory shapes the research, as the intervention was shaped by the goals set out by the HCPs. Illustrating the foregrounding of HCPs' goals, the focus of HIV/AIDS and TB was widened to include other symptoms and types of consultations that HIV/AIDS and TB healthcare providers would encounter. The resources that were implemented as guided by the participating HCPs' feedback address primary goals of HCPs in healthcare consultations, i.e. to communicate with the HCU to provide adequate, effective and timely care in a healthcare consultation.

As illustrated by the goals framework, this research goes beyond an isolated intervention, and considers the broader context of healthcare in South Africa. This theoretical framework therefore lays the groundwork for the empirical studies detailed in this thesis to be understood as secondary goals of improved HCP-HCU communication, to be seen both as a goal with inherent value, as well as a necessary contribution to the primary goal of a decreased HIV/AIDS and TB disease burden in South Africa.

Chapter 4: Methodology

4.1. Introduction

The overarching aim of this research is to improve healthcare provision in HIV/AIDS and TB cases where HCPs and HCUs are unable to speak each other's languages. A mixed methods approach was used, consisting of a participatory action research (PAR) research design on the one hand for creating resources aimed at improving healthcare communication in HIV/AIDS and TB. On the other hand, a cluster randomised waitlist-controlled, pilot feasibility trial was conducted to investigate the efficacy of the resources and training in improving healthcare communication in HIV/AIDS and TB in hospitals and healthcare NGOs in the Eastern Cape, South Africa. This chapter describes the overall research design of this research project, and details the two key methodologies employed, namely PAR and the pilot feasibility trial.

This chapter begins by outlining the research design of each of the studies I conducted and explaining the appropriacy of the mixed methods approach used, and notes – where relevant – the impact of COVID-19 on the research design.

In the PAR section, an introduction to PAR is given, outlining its appropriacy for the needs analyses and pilot feasibility trial while also noting possible challenges and limitations. The general characteristics of action research are outlined, and it is put forth that PAR is the most appropriate type of action research for this project. A timeline for the PAR section of data collection is presented, and the processes of participant involvement are explained. To analyse the data collected in the PAR phase, reflexive thematic analysis was used, which is explained with reference to the steps followed and the relevance of this method. The ethical considerations for this project played a significant role, particularly in the PAR phase of setting up the project, as detailed in this chapter. While a key focus was the feasibility of the intervention, it is also necessary to consider feasibility with reference to the overarching research project, and so this is considered at the end of the PAR section.

The section detailing the design of the pilot feasibility trial begins with an introduction to interventions, the reasons for conducting RCTs, and the appropriacy and potential challenges of conducting a pilot feasibility trial for this research project. The pilot feasibility trial is then detailed as per the Consolidated Standards of Reporting Trials (CONSORT) guidelines (Appendix 24). The data analysis methods are explained, in particular repeated measures of analysis of variance (ANOVA) for a rigorous quantitative analysis, and thematic analysis for a consistent qualitative analysis.

This research was at its intended halfway point when the COVID-19 pandemic began, and due to the research being situated in the healthcare field and initially requiring extensive in-person fieldwork, much of the initial research, including the methodology, had to be changed. The methodology presented here is the methodology of the final study, but in cases where the pre-Covid plan had a significant impact on the adjusted research some details of the initial research plan have been noted at the end of each relevant section.

4.2. Research Design

A mixed methods approach combining qualitative and quantitative research methods was chosen. Mixed methods enable social phenomena to be better understood (Biesta, 2021: 186) and for knowledge to be verified by finding statistical trends and patterns in the data, and at the same time for knowledge to be generated through exploring the contexts and individual nuances of the participants' experiences (Teddlie & Tashakkori in Ivankova, 2015: 4).

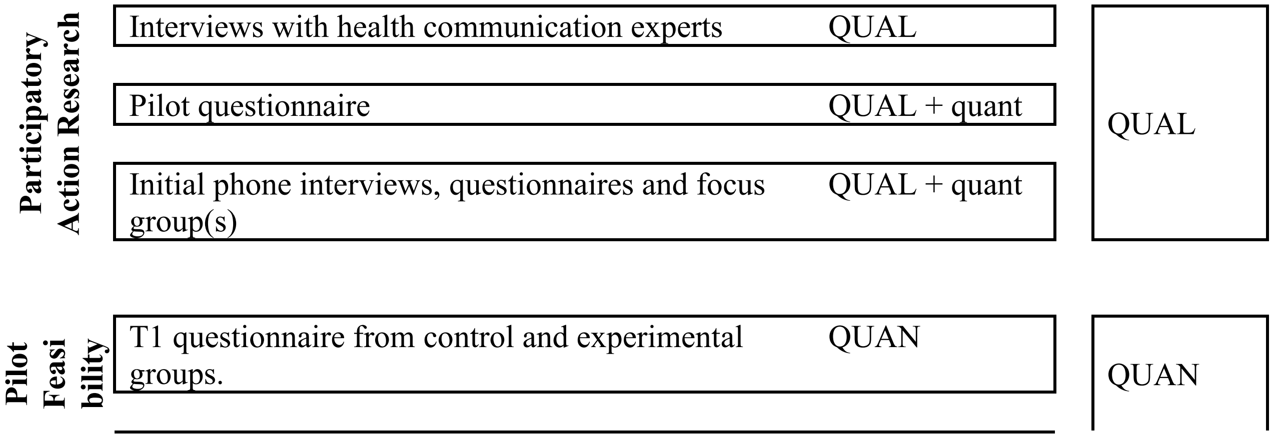
There are five rationales for a mixed methods approach:

1. *Triangulation*, where results are corroborated through the convergence of different methods and designs;
2. *Complementarity*, where results from one method are used to elaborate on, illustrate, enhance or clarify results from the other method or methods;
3. *Initiation*, which seeks out paradoxes and contradictions and uses these to reframe the research question(s);
4. *Development*, which utilises the findings from one method in informing the other method(s); and
5. *Expansion*, in which the research is broadened through different methods for different components (Greene et al., 1989 in Biesta, 2021: 186).

Mixed methods are used in the pilot feasibility trial primarily for the purposes of development and expansion. Following a pragmatic approach, the mixed methods used in this study are guided by the research questions and the aims and objectives of the research, rather than principled on a particular research paradigm, as recommended by Biesta (2021: 186).

Mixed methods can be used at different levels in research: at the level of data, with the combination of text and numbers; through combining methods of data collection and/or data analysis; by using experimental and naturalist designs together; through combining epistemologies; the research purposes could combine causal explanations with interpretive understandings; and in terms of the practical orientations of the research towards producing solutions and developing understanding (Biesta, 2021: 187). This research uses mixed methods at several of these levels: data, methods, and practical orientation, while touching on mixed methods in the epistemological view through the combination of PAR (which typically tends towards an interpretivist orientation) and an intervention study (typically tending towards a positivist orientation).

A mixed methods approach allows for different methods to be used at different stages of the research, such that each method is uniquely appropriate for achieving the objective of each strand[6] of the research (Ivankova, 2015: 52). Mixed methods can be used in concurrent designs, where the qualitative and quantitative components are used together in the same study, and sequential designs, where the qualitative and quantitative components are used at different stages (Biesta, 2021: 188). In both cases, one component could hold greater weight than another. To represent this, ‘QUAL’, ‘QUAN’, ‘qual’ and ‘quan’ are typically used to depict which approach is dominant, with the dominant (or equal) approach depicted in capitals (Biesta, 2021: 188). The use and respective dominance of quantitative and qualitative methods in this study are depicted in Figure 5:



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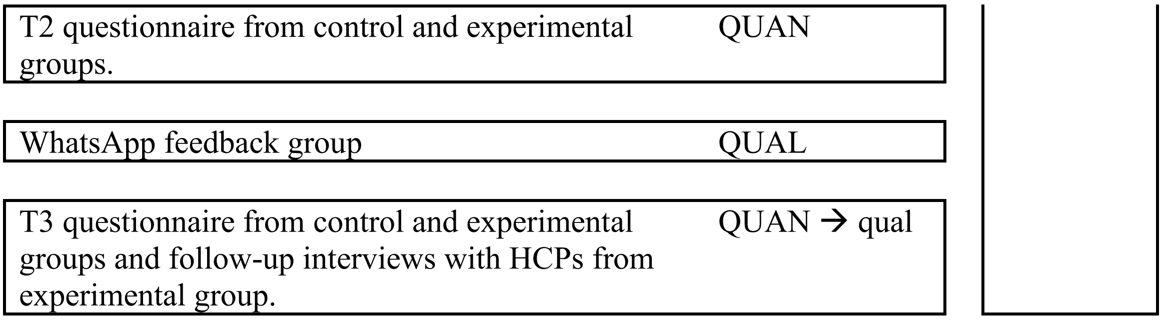
[6] A strand is a part of a mixed methods study comprised of asking a research question followed by data collection, analysis and interpretation (Cresswell and Plano Clark and Teddlie and Tashakkori in Ivankova, 2015: 18)


T2 questionnaire from control and experimental groups. QUAN

WhatsApp feedback group QUAL

T3 questionnaire from control and experimental groups and follow-up interviews with HCPs from experimental group. QUAN → qual

Figure 4: Qualitative and quantitative elements in the studies reported in this PhD thesis

Both the PAR stage and pilot feasibility trial use concurrent designs, respectively emphasising qualitative and quantitative methods. The methodology used in the PAR section employs qualitative priority, that is, qualitative methods are the primary methods used, and quantitative methods are employed to complement the qualitative methods and data analysis (Cresswell and Plano Clark, and Teddlie and Tashakkori in Ivankova, 2015: 19). This predominantly QUAL approach is referred to by Cresswell and Plano Clark (2017, in Biesta, 2021: 18) as exploratory. This reflects the intention of this initial part of the research project (the needs analyses), which aims to explore the explicit and implicit communication models used by HCPs when they are not competent in their HCU's language, and what communication resources and training are appropriate for healthcare provision in South Africa. The pilot feasibility trial predominantly uses a QUAN approach, which "aims to generate causal explanations of societal phenomena" (Biesta, 2021: 189). As such, the sequential QUAL → QUAN overall design was used for this research project to explore and understand phenomena around healthcare communication, and then to test assumptions made about the causes and influencing factors of these phenomena.

Table 1 that follows details each strand of the research in terms of the type of data collected, the research questions the data addresses, the methods used to analyse the data, and the aims of each strand's data collection and analysis. Throughout all stages of the research field notes were taken and a reflective journal was kept by the researcher.

The research questions referred to numerically in the table reflect the research questions outlined in Chapter 3, exploring how HCPs and HCUs communicate (RQ 1), what communication resources and training are appropriate (RQ 2), and the feasibility (RQ 3) and effects (RQ 4) thereof.

	Strand no.	**Data type**	**Research question(s) addressed**	**Method**	**Aim**
Participatory Action Research	1	Interviews with health communication experts	1 and 2	Reflexive thematic analysis	Develop a theory of what is useful to improve healthcare communication.
	2	Pilot questionnaire	1 and 2	Reflexive thematic analysis	Develop a theory of current state of healthcare communication, and of what is used and what is needed to improve healthcare communication.
	Development of draft 'toolbox' of resources and training based on strands 1 and 2				
	3	Initial phone interviews, questionnaires and focus group(s)	2	Reflexive thematic analysis	Refine theory of what communication resources and training are relevant and feasible.
	Development of resources and training informed by theory defined from Strand 3. Development was done in consultation with health communication professionals, language experts, and self-selected participating HCPs.				
Pilot Feasibility Trial	*Participating HCPs were divided into two groups at random: a waitlisted control group and an experimental group. The control group continued practice as normal and the experimental group received the training and resources. Both groups completed T1, T2 and T3 assessments at the same specified timepoints, measuring communication and trust.*				
	4	T1 questionnaire from control and experimental groups.	3	Repeated measures ANOVA.	To investigate the time by group interaction, i.e. to see whether there was a significant difference from T1 to T3 within the experimental group when compared to the control group.
	5	T2 questionnaire from control and experimental groups.	3		
	6	WhatsApp feedback group	3 and 4	Thematic analysis.	To have participants' insights into feasibility; to assess support for the resources.
	7	T3 questionnaire from control and experimental groups.	3	Repeated measures ANOVA.	(See strands 4 and 5)
	8	Follow-up interviews with HCPs from experimental group.	3 and 4	Thematic analysis.	Add detail and nuance to the findings from Strands 4-6.

Table 1: Research design

1.2.1. Impact of COVID-19 on the research design

This research initially planned to include in-person interviews with HCPs, HCUs, and informal interpreters at hospitals in the Eastern Cape; to create resources to be used in HIV/AIDS and TB consultations; to provide on-site training to HCPs to use these resources; and to assess the effectiveness of these resources through a randomised controlled trial (RCT). The RCT would have consisted of three hospitals which receive full resources and training at the start of the trial as the experimental group, and three hospitals which continued with practice as usual and receive the full resources and training once data collection was complete. At the time of the first national lockdown, no on-site in-person interviews with HCPs or HCUs had yet been conducted. Given the lockdown regulations and the necessity for social distancing, protecting vulnerable populations, and remaining conscious of personal safety, the research was restructured to that which is presented in this thesis. Due to the uncertainties at the time of restructuring the research, it was decided that this research would be conducted primarily online. During the course of the research it became possible for in-person fieldwork to resume (to varying degrees at different times), but the primarily online nature of the research was retained (a) for consistency in undertaking the research, and (b) so that findings regarding conducting such research online could be applicable should future lockdowns occur, and to inform conducting research remotely with participants in hard-to-reach locations.

1.3. Participatory Action Research

1.3.1. Introduction to PAR

a) Action research

As indicated by its name, action research (AR) centres action, rather than (only) exploring and describing a situation (Munn-Giddings, 2021: 85). Action research notably came into use through protagonists such as Kurt Lewin (1946) and Paulo Freire (1970/2020), who used action research as a means to create social change through conducting academic research in and relevant to real world contexts (Herr and Anderson, 2015: 12; Hinchey, 2008: 11).

One of the main differences between action research and typical qualitative or quantitative research is the level of control the participants have over the research (Herr and Anderson, 2015: 1). Participants in action research projects may have control as the leader of the research project, or they may be actively involved in the design or methodology of the research (Herr and Anderson, 2015: 1). In action research, "its starting point is the core concerns of a community (geographical or professional) who seek to make positive changes based on the ideas, perspectives and solutions of the people whose lives will be most directly affected by the change” (Munn-Giddings, 2021: 89).

Action research can be carried out by or in collaboration with people typically situated outside of academia. In this way action research redefines who is an ‘expert’. However, I would caution that being “the antithesis of ‘ivory tower’ research” (Munn-Giddings, 2021: 85) does not automatically make the research inherently just or community-focused: the people included, the reasons for inclusion, the voices that are prioritised and the hierarchies replicated through the research could indeed challenge ivory towers, but could also replicate them in new contexts. In line with this, Munn-Giddings (2021: 89) notes that “While AR does not escape broader power dynamics both within research teams and in broader structures, it offers us a process that renders power differentials more transparent.”

Action research is context-specific, reflecting an important tenet of Hulsman’s (2009: 303) goal-oriented theory. Nevertheless, it can be useful to other researchers to learn from and apply similar or adapted processes in different contexts (Munn-Giddings, 2021: 89). The potential for AR to be used as a foundation upon which to build makes it appropriate to inform the pilot feasibility trial, and also reflects an overall aim of this research to explore potential approaches to bridging gaps in healthcare communication as a foundation upon which other researchers, community members, or both, can build upon.

AR studies are typically – although not necessarily – collaborative (Munn-Giddings, 2021: 85). When a distinction is made between AR and PAR, that distinction is often that AR focuses on creating change in practices but does not necessarily involve the participants in the research processes, while PAR actively involves the participants throughout the research process to work together towards social or systemic change (Munn-Giddings, 2021: 86). In the case of this research, the participants were actively involved throughout the research process, shaping not only the ‘action’ but also the research methods.

Action research allows for the research questions to be answered through the creation, implementation and evaluation of an experimental intervention (Cobb et al., 2003: 9), while taking the real-world context of the research into account (Barab and Squire, 2004: 5). PAR in particular ensures that the research further includes the expertise of the participants in the research design processes (Koshy et al., 2011: 5) such that researchers and field practitioners can work together to identify problems and feasible solutions through participatory consensus, ensuring the effects of this research are relevant and sustainable (Koshy et al., 2011: 29).

Action research is typically conducted by or in close partnership with members of the community being studied (Hinchey, 2008: 4), turning traditional approaches around by including subjects as participants, and doing research *with* rather than *on* individuals or communities (Herr and Anderson, 2015: 2). This type of research typically seeks to better understand or address the needs of the community – or, in the framing of Hulsman's (2009) goal-oriented theory, the interlinking *goals* of the community, as deemed important by the community themselves (Hinchey, 2008: 4) and relevant to the specific context of that community (Herr and Anderson, 2015: 6). In order to achieve this the researcher gathers, analyses and reflects on the relevant data in order to create a plan of action (Hinchey, 2008: 4). Rather than simply making recommendations based on these findings, action research includes undertaking the proposed action, after which the cycle of data collection, analysis, and reflection is repeated (Hinchey, 2008: 4). AR is often an iterative process, alternating between and informed by stages of enquiry and stages of action (Munn-Giddings, 2021: 87). Rather than planning a research project from beginning to end, the research is planned, conducted, observed and reflected upon in cycles throughout the project (Munn-Giddings, 2021: 87). In this way action research is often described as cyclical (Hinchey, 2008: 7), where the cycles may be repeated as many times as necessary, or as many times as possible within the parameters of the research project. AR requires that each step of the research be responsive to the preceding step (Munn-Giddings, 2021: 87): the ways in which this is done for this research project are outlined in Table 1 in the preceding section on research design.

b) Participatory action research (PAR) as a type of AR

> Participatory action research (PAR) is like jazz. It is built upon the notion that knowledge generation is a collaborative process in which each participant's diverse experiences and skills are critical to the outcome of the work.
> (Brydon-Miller et al. 2011: 387)

There are several variations of action research (Hinchey, 2008: 6–7) which are held together by their common purpose to identify ways to improve a social problem and their methods in doing so. 'Collaborative action research' implies the research project will be a collaborative effort; ‘critical action research’ implies that the research will be focused on social justice (Hinchey, 2008: 6). PAR incorporates these critical and collaborative elements (Kemmis and McTaggart in Herr and Anderson, 2015: 17–18), focusing on social justice through collaborating with various relevant stakeholders in order to address an issue or issues defined by the community or communities themselves (Hinchey, 2008: 32). This research employs PAR drawing from critical and collaborative action research paradigms: it is critical insofar as it aims to address language-based inequality in healthcare settings, and collaborative as it is on a group’s insights and expertise. While critical research lends itself to creating change, the participatory element prescribes that any change must occur as a result of working together with those who would be affected by such change (Hinchey, 2008: 25). Traditional action research designs typically focus on improving practice on individual or group levels, PAR has a greater emphasis on emancipation across broader levels of society (Herr and Anderson, 2015: 18). While this research does indeed aim to improve practice on individual and group levels, the improvement of healthcare practice in the social context of HIV/AIDS, TB and language in rural South Africa is inextricably linked to emancipation.

Despite the foundational ideas of PAR being incorporated in research since Lewin (1940s), Freire (1970s) and their contemporaries, PAR as a named methodology has been used only relatively recently and has been receiving increasingly more attention. This is illustrated by the increase in publications on PAR seen in Figure 6, which is the number of items returned for a Scopus search for “Participatory Action Research” from 1991–2021. The increase in publications have largely been in the areas of health, welfare and social sciences, and are focused particularly, but not exclusively, on Global South countries (Liamputtong, 2013: 181).

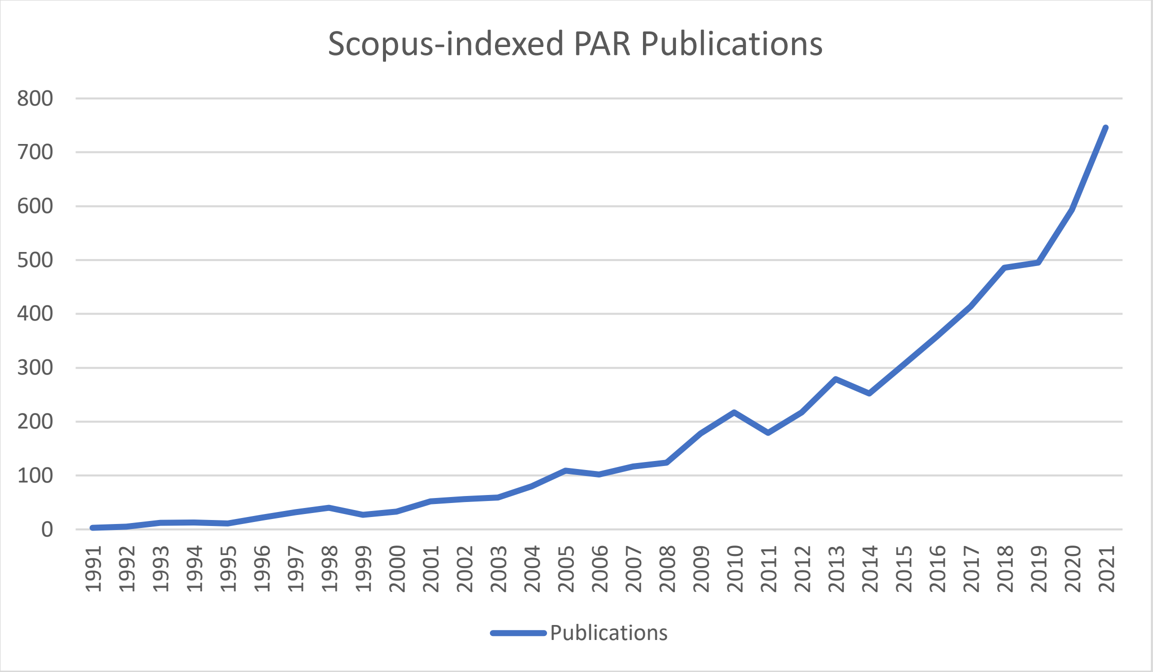


Figure 5: Scopus-indexed PAR publications

In action research the researcher's positionality could be that of an insider or outsider to the community (Herr and Anderson, 2015: 3). Between AR and PAR, the researcher-as-outsider is more common in PAR (Liamputtong, 2013: 184), where the researcher plays the role of facilitating or acting as a catalyst for change together with people who are part of the community or immediately affected by the situation (Munn-Giddings, 2021: 86). However, action research does not require the research to be led by or written up by the research participants; in many cases action research is done by involving the participants in the research design and methodology (Herr and Anderson, 2015: 1). AR with the researcher as an insider of the community is commonly used in education research, while AR with the researcher as an outsider as a facilitator of change is often used in health and social care (Munn-Giddings, 2021: 86). In the case of this research the primary researcher is not a member of the communities participating in the research: I am not a healthcare provider, but rather I participated actively and collaboratively as the language specialist working with HCPs immediately affected by communication barriers.

c) The participants in PAR

PAR can generally be characterised by its integration of theory and practice; its consideration of historical context and macro-level social influences; its aim to bring about social change; the collaboration between the researcher and the community; and the outcome of the research being applied practically (de Schutter and Yopo in Herr and Anderson, 2015: 17). In order to achieve this the researcher and community should as far as possible work together in planning, maintaining and disseminating the research, with cognisance of all members' perspectives and contributions (Eisinger and Senturia in Ivankova, 2015: 31). In this way the research is always done by or together with members of the community (Herr and Anderson, 2015: 3).

A key characteristic of PAR and indeed action research more broadly is the cyclical nature of the research process; in PAR the different skills and experiences of the various community members should be used throughout these research cycles to ensure relevant expertise in each step (Schulz et al. in Ivankova, 2015: 31–32). This was achieved by creating various channels of communication through which participants could provide feedback on the resources and training, at different points.

Different forms of PAR can be characterised by the form of collaboration, specifically whether it is an insider from the community collaborating with outsiders (such as academics or consultants) or vice versa. This research takes the more common form of outsiders in collaboration with insiders (Herr and Anderson, 2015: 49). In this case, the primary stakeholder(s) are the HCPs, who will reflect on and discuss what they think possible strategies could be, the feasibility of the training, and the success of communication resources. The secondary stakeholders are the HCUs, who receive the improved communication and benefit from the resources, but were not directly involved in the research collaboration.

A potential challenge of PAR is ensuring all participants' voices are heard, and that all expectations are managed. In order to do this, participants' expectations and the researcher's capacities needed to be discussed in an open manner at the beginning of the research (Herr and Anderson, 2015: 50).

While HCPs often hold more social power than their HCUs, they may still be concerned that participation, or lack thereof, in this study would affect their position. For example, HCPs may have felt like they were being evaluated. It was explained to HCPs that this research was not to review their skills within their job, and also that the information gathered would not be shared until it was fully anonymised. The purpose of the research, specifically that it was trying to gather information of what is actually needed, what HCPs and their HCUs are experiencing, and their suggestions for improvement, was carefully explained to participants in as much detail as desired or required.

d) *Appropriacy of PAR for this research project*

The reason at the forefront of using PAR for this research project is so that this research benefits not only myself and the academic world within which I am situated (Herr and Anderson, 2015: 95), but specifically the communities and participants affected by communication barriers in healthcare. PAR as a research design is able to give more credibility to this research project as it allows the researcher to better engage with participants and ultimately to undertake an experimental intervention that is most likely to succeed within the given contexts. "The history and practice of AR challenges assumptions about who can do research, how it might be undertaken and who decides its worth" (Munn-Giddings, 2021: 89), and as such the foundational ideas of AR can also be used to support decoloniality in academia. Specifically, PAR draws on the indigenous, context-specific and community knowledge of the participants, which gives unique insight into the problems they experience, as well as their suggestions for how to alleviate these problems.

In line with this, the methods were continually adjusted based on participants' suggestions; again, reflecting Hulsman's (2009) goal-oriented theory, with the intervention being responsive to participant's goals. In the context of the methods, the primary goals were typically set by the researcher (e.g. to have a focus group discussion), while the secondary goals (i.e. the steps take in order to achieve the primary goals) were defined by or together with the participants. While phone call interviews were initially planned to gather feedback on the suggested resources, one Head of Department suggested a video presentation rather be sent and a printable questionnaire, while another suggested a focus group over Zoom. These adaptations were made possible by consistently and clearly asking participants what methods would be most suited to their contexts. The development of the project also continued in a way that was responsive to the wants and needs of participants, for example some participants requested that they be consulted before the resources were finalised because "people are more likely to use something if it includes what they think is important" (Dr X).

There is some contention regarding whether PAR is a methodology or simply a way of approaching the research project and research participants (Cammarota and Fine, and

Cochrane-Smith and Lytle in Herr and Anderson, 2015: 1). In the case of this research, PAR is used as a research design in order to inform the overall approach to the research. As is common in action research (see Munn-Giddings, 2021: 87), a mixed methods approach is used as the methodology to further inform the more detailed data collection and analysis elements of this research project.

I We know They know	II We don't know They know
III We know They don't know	IV We don't know They don't know

Figure 6: Luft's Four Squares of Knowledge (Herr and Anderson, 2015: 50)

Academic research in communities outside of academia often result in the researcher placing themselves in quadrant III, reinforcing participants' placement of themselves in quadrant II (Herr and Anderson, 2015: 50). Through PAR this research aimed to build inclusive relationships such that the researcher and participants would increasingly place themselves in quadrant I together (Herr and Anderson, 2015: 50); more detail on how this was done is provided in Chapter 7. This was facilitated through the research design beginning with needs analyses; by explicitly stating to HCPs that their insight was sought as the experts in their field, to collaborate with language experts; and through asking questions seeking HCPs' thoughts and advice on moving from one step of the research to the next.

This project was approached with the understanding that if the communication resources and training proved to have a positive impact on participants, participating hospitals would be encouraged to continue using the communication resources so that HCUs could continue to benefit from improved HCP-(interpreter-)HCU communication. In the case that the model required revisions, those revisions would be made and communicated to these hospitals so that they could, if they chose to, provide the best possible support for communication between HCPs, HCUs and interpreters. With participants' support, it would be possible for the models' continued use and further development after the study finished, particularly as the participants would have been integral to the development and implementation of these models and as a result would be better equipped to maintain and develop them themselves.

While a key focus of PAR is to ensure the findings of the study are disseminated among participants and their communities, this research project incorporated a mixed methods methodology in the form of a pilot feasibility trial with the aim of ultimately making the results generalisable to communities other than those that participated in the study. An important aim of this research is to improve social equity through improved access to healthcare via the communication resources used by HCPs. The training materials for the resources are available online, with a creative commons license making them freely accessible to anyone. As such, HCPs who participated in the pilot data collection, but did not participate in the pilot feasibility trial and as a result did not participate in the training, can access these, if they wish. Similarly, anyone who wishes to use these materials is able to access them freely on the *Healthy Talk* website (healthytalk.co.za).

e) Using PAR to navigate language and power

PAR potentially ties to decoloniality due to its history originating in Global South countries, and its concern with addressing social inequalities between dominant and marginalised or oppressed groups of people (Liamputtong, 2013: 184). Writing specifically about PAR and healthcare, Tandon (1996: 25, as paraphrased in Liamputtong, 2013: 190) asks: "Whose interests do health sciences, research in health care, knowledge about health care, and health practices serve? Who has control over health, health care, health science, and health research?" These questions are central to decolonial approaches in research (T. Goniwe, 2022, personal communication, 12 July).

However, PAR approaches are not by definition decolonial nor do they necessarily challenge or question existing power structures, as research that prioritises the interests of HCPs rather than HCUs can "perpetuate the current system of inequality and injustice related to health and health care" (Tandon, 1996: 25, as cited in Liamputtong, 2013: 190). Even though PAR challenges ivory tower research, I urge that each part should still be questioned for who are the 'knowers', whose knowledge is valued, who can be a 'researcher', who is the so-called 'oppressed', and when and why are they assumed to be mutually exclusive[7]. In addition to the

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[7] Indeed, in contexts where higher education is inaccessible to the 'oppressed' it is likely that the contrast of 'researcher' and 'research subject' could be replicated as mutually exclusive. In the case of South Africa, a country with deep inequalities, higher education has become increasingly accessible, first after the fall of apartheid and secondly after the #FeesMustFall protests of 2015. Because of this, the possibilities for and occurrences of the 'researcher' and ('oppressed') 'research subject' being mutually inclusive have increased.

possibility to reproduce rather than challenge existing power inequalities, I argue that those who use PAR approaches should also be cautious of reproducing paternalism through holding a minimalistic view on the agency of the participants, as is seen in the view of de Koning and Martin (1996: 4, as cited in Liamputtong, 2013: 183) that PAR "assists those who are marginalised and deprived to 'gain self-confidence and pride in being able to provide a useful contribution to community life'".

Rather, in order to truly serve the participants, an approach such as that suggested by Tsey et al (in Liamputtong, 2013: 183) should be followed:

> PAR, according to Tsey and others (2004, p. 70) sees 'peoples as the experts in their own lives, who should necessarily be actively involved in decision-making, planning, and then both implementing and reviewing change'. …. PAR is therefore 'an [alternative] empowering methodology to conventional research practices that have been perceived, in some contexts, as acts of colonization, whereby research and policy agendas were imposed on a local group or community by people far removed from local concerns or interests'.
> (Liamputtong, 2013: 183)

When considering PAR, the value and contributions of participants should be seen as equal to those of the researcher (Liamputtong, 2013: 182). Perhaps seemingly paradoxical to the above arguments, I further argue that PAR should not be considered solely in terms of its value to the community, but also in terms of its value in academia. The aim of PAR is clearly to make a positive, real-life difference with and for the participating community; however, its role in enriching and decolonising academia through foregrounding the voices and knowledge of those typically situated outside of academia should also be recognised as a valuable aim. If this was not the case, why should researchers engage with a community and also translate it to something academic rather than simply provide resources? In line with this, Tandon (1988, in Liamputtong, 2013: 186–187) recognises PAR as a means of building and sharing alternative sources of knowledge production.

This research attempts to redress a structural issue of disempowerment through language in healthcare, via a mid-level (i.e. not quite top-down nor bottom-up) intervention, with the objective of creating recommendations that can be implemented at a structural level. This research did not work directly with the community who is disempowered through language, but rather with part of the community who – albeit unintentionally or despite their best efforts

– are complicit in this structural disempowerment of people based on their language proficiencies.

1.3.2. Participant involvement

The participant recruitment and data collection were revised when the COVID-19 pandemic began, taking into consideration potential risk to participants and the researcher, and logistical difficulties due to lockdowns. Once it became clear that COVID-19 would have an impact far outlasting the initial four-week lockdown, it was decided to conduct all of the research remotely. Naturally, this had a significant impact on participant involvement.

As healthcare sites often run slightly differently, particularly with regard to organisational structure, participant recruitment was approached with the understanding that the logistical arrangements made at one site was not necessarily suitable at another. Management of each hospital was contacted by phone or email to enquire about the possibility of conducting research at this site. Once a site indicated its interest, permission for that specific site was sought, often in the form of an additional application to the site's research ethics committee. Upon receiving permission at each site, the researcher also received the contact details of the key or initial contact person at each hospital: sometimes this was the Medical Services Manager, other times it was the Head of Internal Medicine or the Infectious Disease Specialist. The researcher then emailed the primary contact with a letter explaining the study, and to set up a phone call. The initial phone call was used to introduce the researcher, explain the study and answer any questions about the study, confirm their interest in participating, and discuss the logistics of the research. With the initial participant the researcher had suggested conducting individual phone interviews with other participants at the hospital, but they suggested that instead the researcher should send a video presentation and printable questionnaires, so that this could be done in the morning meeting. In line with PAR principles, thereafter both options were presented to other participants in the initial phone call, and all other participants agreed with the suggestion of the presentation and questionnaires.

As the researcher was not present to conduct or oversee the informed consent process, the informed consent sheets themselves were of particular importance. The first step of the research involved a questionnaire, so participants could potentially opt in to do the questionnaire only, and furthermore could opt to only answer as many or as few questions as they would like. Thus, the worst-case scenario was that someone who did not choose to participate would at most have to watch a video presentation and then submit an empty questionnaire. In making these arrangements care was taken to (a) ensure participants did not feel undue pressure to participate, and (b) minimise interruption to the daily workings of the clinic or hospital. However, it should be noted that the dynamic could potentially be influenced by the person sending the questionnaires back to the researcher.

The above processes were followed for both the first and second stages of the research, i.e. when the researcher was investigating current practice and later when the communication model was implemented. Consent was continuous: even if people participated in the first round of data collection, their consent was sought again for the second round of data collection.

1.3.3. Timeline

The timeline for the PAR data collection was as follows:

May 2019
In-person interview with health communication expert

August 2020
Needs analysis #1: Pilot questionnaire study

February 2021
Zoom interview with health communication expert

March 2021
Zoom interview with health communication resource developer

May – August 2021
Needs analysis #2: WhatsApp phone interviews with department heads at participating sites, printed questionnaires with participating HCPs, Zoom focus group discussions with participating teams.

1.3.4. Strand 1

a) Interviews

The first step of the data collection process (Strand 1) was to interview health communication experts. These were semi-structured interviews conducted with health communication researchers and health communication resource developers. The first interview was conducted in person and subsequent interviews were conducted via Zoom. The aim of these interviews was to learn more about the work these participants had already done, specifically health communication resource and training development and implementation. The interview schedule (Appendix 12) was adjusted depending on the specific expertise of the participant, and included a selection of questions about:

- Their processes of resource and training development;
- Sustainability of interventions and resources;
- Barriers to implementation;
- Health communication training at South African universities;
- Research methodologies, particularly PAR;
- Communication strategies;
- Medical terminology in South African languages;
- The use of visuals in communication resources;
- Practicalities of resources;
- The role and training of interpreters;
- The possibility to use the resources and training they had created, and/or collaborate with them.

b) Sampling for Strand 1

Purposive sampling was used to select participants for Strand 1: people who had either published research on health communication in South Africa or had created health communication resources were reached out to via email to request an interview. Those who responded to the researcher’s request for an interview were included in this study.

1.3.5. Strand 2

a) Pilot questionnaire

This strand constituted what Tymms (2021b: 278) termed ‘exploratory work’. The pilot questionnaire study was an opportunity to (a) explore health communication as experienced by HCPs in South Africa, and (b) to test the feasibility of an online study following the Covid-adjustments discussed in the introduction.

A pilot descriptive study was conducted between August and October 2020 using an online questionnaire. The aim was to do an explorative scoping review of HCPs working with HIV/AIDS and/or TB, focusing on communication strategies and unmet needs. This study was conducted online using the SurveyMonkey platform (Appendix 13). The survey consisted of: an information page describing the study, an informed consent page with opt-in consent to participate; several closed-ended, yes/no or checkbox questions about languages spoken, use of apps, job and workplace descriptions; Slider Scale questions about communication with HCUs; optional, open-ended questions exploring specific communication difficulties, strategies and suggestions; and options for follow-up communication. The SurveyMonkey inbuilt tools estimated a completion rate of 60% and an estimated completion time of 15 minutes to complete this survey.

b) Sampling for Strand 2

Convenience and snowball sampling was used for the pilot questionnaire, and the questionnaire was shared publicly online on the project's website and the researcher's Facebook and Instagram accounts. Anyone in South Africa who provides healthcare for people living with HIV/AIDS and/or TB was eligible to participate in this study.

Conducting a survey online has the potential to be impersonal and for targeted participants to feel distrustful or disinterested. By using snowball sampling an advantage was gained, as the people approached to participate already trusted the researcher or were interested in the research, and this trust and interest could be passed from participants known to the researcher, to participants known by other participants. A possible limitation of this, however, is that the demographic characteristics of the participants are more alike to those of the researcher and her circle of contacts than representative of HCPs in South Africa. Furthermore, the online nature of this survey limits this study to only include HCPs with internet access and at best an interest in and at the least the technical capabilities to participate in an online survey.

1.3.6. Strand 3

a) Feedback on resources

A ‘resource preview pack’ (Appendices 19 and 20) was created based on the literature, the feedback from the pilot questionnaire study, and recommendations and possibilities from interviews and partnerships with other health communication experts. This pack was designed to show a brief overview of possible resources, upon which HCPs could give feedback to help the researcher and the research team further refine these resources. The group involved in reviewing this resource pack consisted of different participants to the initial group: this was primarily (a) due to restrictions from lockdown regulations at different times of the COVID-19 pandemic, and also (b) allowed for feedback from a broader community of HCPs. In cases where HCPs’ feedback could not be directly implemented, their feedback was still used as closely as possible to guide adjustments that could be made.

The suggestion to develop the resource preview pack into a video presentation came from the Internal Medicine consultant at one of the sites. In an initial phone call with the researcher, she suggested that instead of the researcher trying to contact everyone in her team individually to send them the resource preview pack, the researcher could send a video presentation and printable questionnaires, which she would show to her team during one of their morning meetings. It was for this purpose that the resource preview video (Appendix 19) was created. The accompanying questionnaire (Appendix 14) included questions about the participant’s language proficiencies and any health communication resources or training they may have experience with, and then used a Likert scale to assess how likely each participant was to use each resource with their HCUs, with space for comments on what should be included in certain resources, or what should be considered for certain resources.

In the initial phone conversation with the Infectious Disease specialist at another site, the researcher offered the options of sending the presentation or questionnaires or having an online focus group discussion. The Infectious Disease specialist suggested that the researcher and their team have a Zoom focus group discussion. For the focus group discussion, the researcher presented the resource preview pack presentation (Appendix 20) and conducted a focus group discussion (Appendix 15). The focus group discussion explored questions about usefulness and feasibility of each resource, what resources the participants already find useful, as well as suggestions for improvement and any other considerations to keep in mind.

b) Sampling for Strand 3

Initially, clinics, hospitals and healthcare centres were chosen based on their geographic location in the Eastern Cape, with the aim to include a mix of sites in rural, semi-rural and urban areas. However, hospitals then became the main focus because they are the sites at which more staff do not speak local languages. A variety of hospitals were approached, but it was then found out that after receiving ethical clearance from the Eastern Cape Department of Health it was necessary to receive ethical clearance from each district in order to conduct research at several of the proposed sites, while at the tertiary and provincial hospitals the additional ethical clearance could be sought through the hospital's REC directly. In the interest of time, the latter was chosen as the focus. This meant that all sites included are either in urban or semi-urban areas. They are all public hospitals. Conducting the research online also limited the capacity for rural hospitals to participate in cases where network connectively was poor, but, more importantly, two of the rural hospitals that did respond to the research request informed us that they were unable to participate because they were "swamped". This illustrates the difficulty of conducting research in hard-to-reach areas, and the importance of considering the generalisability of the results for these contexts. This limitation will also be discussed in Chapter 7 and Chapter 8.

Participants were recruited through snowball and convenience sampling. The initial aim was to include six hospitals, with at least four HCPs from each hospital, who would complete the measures about four HCUs each, which totalled 24 HCPs reporting on 96 consultations (for more details on the power analysis, see below). However, it was not logistically possible to include six hospitals, so individual HCPs were approached to participate in addition to the HCPs from participating hospitals, and snowball sampling with used to recruit more participants.

This research was aimed at HCPs who already care about – or are to some degree interested in – communication as part of their practice. This research will investigate, for HCPs who already might want to do something to improve communication with their HCUs, what types of resources are most suitable and why.

It is hoped, however, that by including a hospital-based approach and including people who otherwise might not have been interested in improving their communication, that an awareness around communication will be built, and even that positivity or motivation can be improved by seeing something like this in action. There is though also the possibility, if we make it cumbersome, that it could reinforce the idea that communication is too difficult and an insurmountable obstacle.

1.3.7. Reflexive thematic analysis

Thematic analysis allows for themes which “capture the essence and spread of meaning” (Braun et al., 2019: 845) to be identified in qualitative data. Thematic analysis allows for data to be grouped and understood based on shared and explicit and underlying meanings, across different contexts in which it occurs (Braun et al., 2019: 845). Of course, themes are not immediately recognisable in a dataset, and so in order to identify them the data is examined and ‘codes’, or smaller units of meaning, are identified (Braun et al., 2019: 845), and then through a step-by-step process these codes are grouped together to create themes. Thematic analysis was chosen because it looks beyond the surface-level or semantic level of what was said (Braun et al., 2019: 845), and seeks to find and group together the underlying meanings.

Thematic analysis can be divided into three main approaches: reflexive, coding reliability, and codebook thematic analysis (Braun et al., 2019: 847). Reflexive thematic analysis was chosen to analyse the data from Strands 1, 2 and 3, because it allows for understandings to emerge from, rather than be imposed on, the data. In reflexive thematic analysis, codes are created by analysing and exploring the data, and the themes emerge relatively organically, based on the researcher’s interpretation and grouping of the codes (Braun et al., 2019: 848). This contrasts with, for example, codebook thematic analysis, where certain codes are already identified and the researcher looks specifically for those codes in the dataset.

Reflexive thematic analysis is conducted in six steps:

1. Familiarising oneself with the data by reading through it in a relaxed way and making casual notes, while actively engaging one's curiosity about the data (Braun et al., 2019: 852). In this step one should aim to notice things of interest, without worrying about what formal labels to give these things (Braun et al., 2019: 852).
2. Generating codes by systematically engaging with the data in more detail, in order to add labels or 'codes' to pieces of data (Braun et al., 2019: 853). In this step, one should code both the semantic data, as well as the latent data (Braun et al., 2019: 853).
3. Constructing themes by using 'candidate themes' from the initial research phases, and testing their appropriacy for bringing together the codes (Braun et al., 2019: 854), or from developing significant codes into broader themes (Braun et al., 2019: 855).
4. Revising the candidate themes by keeping the themes that fit and removing those that do not (Braun et al., 2019: 855).
5. Defining the themes by deciding the names, the boundaries and central concepts of each theme (Braun et al., 2019: 855).
6. Producing the report by writing up the data analysis, while also testing how well the themes work on their own, in relation to each other and the data, and within the full write-up (Braun et al., 2019: 857)

1.3.8. Resource development

The data collected in strands 1-3 informed the creation and refining of the resources and training. The details of the resources and training are given in Chapter 6: Materials Development. In line with the participatory nature of this research, those participants who self-selected to provide additional feedback on the resources were contacted at different phases of the resource development to give feedback on the content and usability of the resources, where applicable.

1.3.9. Ethical considerations

a) Development and adaptations

Before COVID-19, this project aimed to include the perspectives of both HCPs and people living with HIV/AIDS and/or TB who used the healthcare services at the participating sites. The confidentiality of healthcare provision and reception, and the stigma attached to HIV/AIDS (see for example Chasi, 2014: 46) and, to a lesser extent, TB, required rigorous consideration to be given to the ethical conduct of this research project. An ethics application was submitted to the University's School of Languages Research Ethics Committee; then to the Rhodes University Ethical Standards Committee (RUESC), after which revisions were required and it was resubmitted and accepted; thereafter an ethics application was submitted to the Eastern Cape Department of Health. The researcher was in the process of seeking approval from the Department of Health District offices in the Eastern Cape when South Africa went into its first lockdown. The COVID-19 pandemic necessitated an adapted approach to the research, and it was decided to move everything online and/or remote. This meant, unfortunately, that the risks involved in collecting the valuable perspectives of the HCUs would outweigh the potential benefits, and it was decided to focus only on HCPs' perspectives. This is, unequivocally, a limitation of the research, and any further research should actively seek to include these perspectives when it became safe to do so.

Removing the risks associated with the at-risk group of healthcare users did not mean the ethical risks of this research were altogether minimised: on the contrary, conducting research online and remotely carries a host of risks in itself. The two most important risks to be aware of were data security and participant consent.

b) Data security

Due to the highly confidential nature of the data collected in this research the secure collection, storage and destruction of data is of extreme importance. This was done in accordance with Rhodes University's ethical standards guidelines for data management and storage. For the pilot questionnaire, SurveyMonkey was used. Participants' IP addresses were not tracked.

c) Informed consent

A foundation of ethical research is that all participants are participating by their own free will, and do not experience any undue pressure or coercion to participate.

Participants had legal capacity to give consent as they were all over 18 years of age, and they were all in a fit mental state to do so. It was important that all research participants were competent, that is, that they were able to understand the research objectives, why they were invited to participate, what their participation would involve, the risks and benefits they may encounter as a result of participating, and that they could withdraw from the research at any time. In order to facilitate this, all participants received an information sheet (Appendices 5–

11) that included a description of the nature of their involvement, the duration of their involvement, the purpose of the research and how the research will be conducted. The potential risks to the participant were also described, together with a description of how these risks would be minimised or dealt with should they occur. The potential benefits, both to the participant and overall, were also presented. If a participant did not fill in and sign the consent sheet attached (Appendices 5–11) to the information letter, they were not included in the study.

For the pilot questionnaire, participant consent was given in an online form (Appendix 6). In this case, participants could not physically sign the form, and so they were presented with opt-in boxes which they had to actively tick to indicate their consent, and then write their name. Pseudonyms were not used to complete the pilot questionnaire as the assessed risk did not require this. Furthermore, because participants were completing this online and in their own time, and no-one but the researcher would know whether or not they had completed it, they did not experience external pressure to complete it, thus every step of the pilot questionnaire was opt-in only.

d) The system is offline

The South African adage of ‘the system is offline’ refers to when it is not possible for something to be done due to a technical difficulty. This affected the research timeline with the initial ethics application for instance, which needed to be resubmitted a few months later due to a new system being implemented at the university in the following year; and affected participant recruitment due to several emails to potential sites and participants going unseen because the local email server was down.

1.4. Pilot feasibility trial

1.4.1. Background

Tymms (2021a: 179) defines an intervention[8] as “a deliberate attempt to change the world in some way with a view to assessing the impact of that intervention.” An intervention can also be referred to as a trial or an experiment (Tymms, 2021a: 179). Interventions are typically conducted either with individuals or with groups, often by assigning groups to different

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[8] The connotations of the word ‘intervention’ are hereby also acknowledged. An intervention – in lay terms – often has authoritarian or paternalistic connotations, which is in direct contrast to the participatory processes and ideas of the PAR methodology also used in this research. As such, ‘intervention’ is used here for its scientific meaning.

treatment options (Tymms, 2021a: 179). When trials are designed for groups, or ‘clustered’, the aim is typically to investigate how something works as part of a system, rather than how it works for each person (Tymms, 2021a: 182). A waitlist-controlled trial refers to an intervention where a new treatment is assigned to one group and the other group(s) only receives the treatment after the end of the intervention in the first group, so that at the end of the trial all participants have received the treatment. An intervention conducted with groups made up of individuals within pre-specified organisations, for example schools, hospitals, classrooms or teams is typically a clustered randomised control trial (RCT) (Tymms, 2021a: 179).

This section outlines the rationale for using an RCT to assess a health communication intervention, describes the reasons for beginning with a pilot feasibility trial, and details the methodology of a pilot feasibility trial in this study.

a) Rationale for a future definitive RCT

Randomised controlled trials (RCTs) were initially used in behavioural and psycho-social research, and gained popularity in clinical medicine research as it provides ways to test treatments in a way that minimises bias, is less susceptible to false conclusions, and is an ethical approach when there is uncertainty about which treatment is best (Stephenson and Imrie, 1998: 611).

RCTs can be designed to test efficacy in a controlled or sterile setting through explanatory trials, or to test effectiveness in a real-world setting through pragmatic trials (Stephenson and Imrie, 1998: 611). These trials can be used to replace before and after comparisons in behavioural interventions, as the latter may show an improvement that is not necessarily attributable to the intervention (Stephenson and Imrie, 1998: 612). An RCT with multidimensional assessment through a package of outcome measures allows for correlations between different measures to be drawn, even when a single measure on its own may not show statistically significant results (Carding and Hillman, 2001: 645).

While the aim of an RCT is to evaluate an intervention’s efficacy or effectiveness, the aim of a pilot feasibility trial is to assess how feasible it is to conduct such an RCT (Eldridge et al., 2016b: 2), whether that RCT would be conducted by the same researchers or by others who read the study (Shanyinde et al., 2011: 8).

b) The present pilot feasibility trial

Feasibility and a feasibility study are defined respectively as "a concept encapsulating ideas about whether it is possible to do something and … *a feasibility study asks whether something can be done, should we proceed with it, and if so, how*" (Eldridge et al., 2016a: 8, italics in original). While the term 'pilot study' is sometimes conflated with the meaning of 'feasibility study' (Eldridge et al., 2016a: 2), a pilot study also implements part of the study as one would in future practice (Eldridge et al., 2016a: 8). A pilot feasibility trial is therefore an intervention which aims to discover whether a full trial – typically an RCT – could be conducted, while also conducting some part of the intended future trial on a smaller scale (Eldridge et al., 2016a: 8). Given the restrictions of time and resources, and particularly the restrictions of the COVID-19 pandemic, a pilot feasibility trial was chosen for this study in order to explore the possibilities of developing this research further and conducting a trial on a larger and more definitive scale.

Randomised trials are typically reported using The Consolidated Standards of Reporting Trials (CONSORT) statement, which facilitates transparent and quality reporting (Eldridge et al., 2016b: 2; Tymms, 2021a: 182). The CONSORT statement has been extended for pilot feasibility studies (see Eldridge et al., 2016a) and has been used in reporting on the pilot feasibility trial in this study. The accompanying checklist can be found in Appendix 24.

It has been argued that RCTs are unethical because potentially beneficial treatment is withheld from the control group (Stephenson and Imrie, 1998: 612). This could similarly be extended to pilot feasibility studies; however, while this warrants a careful examination of any intervention study to determine whether improved treatment is being withheld, this is of lesser importance to a study such as this one. In this study the intervention aimed to provide an improvement to treatment as usual – an improvement that, it is hoped, would have long-term effects of HCUs' health and HCPs communication practices, but is unlikely to have an effect significant enough to warrant rolling it out across both groups, particularly before it had been assessed and improved. And – more importantly – it is a wait-list controlled study, thus all participants will receive the intervention relatively quickly.

In clinical trials, 'blinding' is often used by providing the control group with a placebo, so that participants are effectively 'blind' to which treatment arm they have been allocated

(Stephenson and Imrie, 1998: 612). In behavioural and psycho-social research blinding in this manner is naturally more difficult, and so the assessment of the outcome may be blinded: the person or people who assess the outcomes do not know to which treatment group participants were allocated (Stephenson and Imrie, 1998: 612). Due to the relatively small size of the team for this research true assessment blinding was not possible. This is a limitation of this study, together with the possible bias of HCPs in the self-reported measures, which may have been influenced by their knowledge of being assigned to the treatment or control group.

In the real-world context, there are numerous factors that could impact the effectiveness of the studied treatment – particularly socio-economic and psycho-social factors (Stephenson and Imrie, 1998: 612). This context is further reflected, for example, by the assertion of Hulsman's (2009) goal-oriented theory that communication abilities also rely on perceptual and behavioural skills. An advantage of the randomised nature of an intervention is that these non-treatment factors can be balanced out and accounted for; however, a drawback of an intervention such as an RCT is that these factors are not investigated and explained (Stephenson and Imrie, 1998: 612). Qualitative methods may also be used with interventions (Carding and Hillman, 2001: 645), and it is for this reason that a multidisciplinary approach with a mixed methods methodology is used, so that this research could assess the efficacy of the proposed resources and training, and also understand the factors that facilitate or hinder its efficacy.

1.4.2. Aims and Hypotheses

The pilot feasibility trial focused on research questions 2, 3, and 4, examining which communication resources and training are appropriate for the provision of HIV/AIDS and TB healthcare in South Africa, the feasibility of their implementation and evaluation, and the effects of these suggested communication resources and training on healthcare provision.

These research questions were explored with the aim to analyse the effects of the communication intervention in terms of feasibility of implementation and satisfaction.

Feasibility of implementation was considered in terms of:

1. Recruitment of sites,
2. Recruitment of HCPs at participating sites, and
3. HCPs' participation in questionnaires, WhatsApp feedback group and interviews.

Satisfaction was considered in terms of:

1. Participants' self-reported use of the proposed resources, and
2. Qualitative feedback in the WhatsApp feedback group and interviews.

Feasibility played a significant role in sampling. Initially the focus of this project was on rural healthcare sites; however, this was changed to urban and peri-urban sites due to accessibility and the COVID-19 pandemic. Of the rural sites that responded to the researcher's initial invitation to participate, both stated that, while they were interested in the research and believed it was an important study, they were unable to participate because they were too busy and understaffed. When the research moved online/remote due to the COVID-19 pandemic, urban and peri-urban hospitals were also chosen because they (while also often understaffed) were more able to participate, often also with better internet access.

2.4.3. Description of the intervention and timeline

Participants were recruited between April 2021 (during the second needs analysis study) and April 2022, and sites were randomised in March 2022. The control group continued with their practice as usual. Each participant in the control group received an information letter and consent sheet, and a questionnaire booklet. Each participant in the intervention group received an information letter and consent sheet, together with the '*Healthy Talk* Communication Pack'. This pack contained a communication booklet that included the questionnaires, and the communication resources (see Chapters 6 and 7 for more detail). Participants in this group were encouraged to use the resources as much or as little as they would like. Wherever possible, T1 was conducted in person at the time of signing up for the study and receiving the *Healthy Talk* Communication Pack in April 2022. T2 was conducted four weeks later, in May 2022. During the same week that the T2 questionnaire was being collected, the WhatsApp feedback group was conducted. T3 was then conducted in June 2022, six weeks after T2 and the WhatsApp feedback group. Follow-up interviews were conducted in the week following T3.

Both groups were requested to complete and return their questionnaires at specified timepoints. In most cases participants took photos of their questionnaires and sent them to the researcher via WhatsApp. In cases where participants had lost their booklet or did not have it with them at the measurement moments, they were sent a link via WhatsApp to complete the questionnaire online through a SurveyMonkey form. At one of the control sites the participants completed the questionnaires in their booklets, and the booklets were collected by a member of the research team at the end of the trial.

2.4.4. Design

This pilot feasibility trial was a waitlist-controlled cluster-randomised study. The sites (four hospitals and two NGOs providing healthcare services) were the clusters, and thus all participants in each site were allocated to either the control or experimental group. Both groups completed the same scale for the T1 to T3 questionnaires; the intervention group also answered questions on the use of the resources in addition to these questionnaires; and the intervention group participated in a WhatsApp feedback session and follow-up interviews after T3. At the end of the study, the control group received all resources from the intervention, and both groups also received additional resources created in response to the feedback received.

2.4.5. Participants and procedures

a) Sampling

Sites were recruited in the PAR stage of this study, following the steps outlined in the *Participant involvement* section of this chapter. The settings and locations of each site are described in Chapter 7. Once key people had been contacted at each site, snowball sampling was used to recruit more participants at the sites. The sampling criteria was any HCP who provided healthcare services to people living with HIV/AIDS and/or TB. Participants were not chosen based on language or specific healthcare profession.

b) Sample size

A power analysis (detailed in the *Analysis* section of this chapter) determined that the minimum sample size required for a feasible RCT[9] and to be able to conduct a sufficiently powered ancillary analysis was 18 participants, with nine participants in the control group and nine participants in the intervention group.

c) Randomisation

As this was a cluster randomised waitlist-controlled pilot feasibility trial, all participants were randomised to either the intervention or waitlist-controlled group. This randomisation was

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[9] With conditions described in the power analysis.

done by site using the *Team generator* on randomlists.com. All participants were clearly informed about the design of the study before randomisation, and after randomisation all participants were informed which group they were assigned to (i.e. there was no blinding).

2.4.6. Outcomes

a) Outcome Model

As all participants were healthcare professionals who have already received training, and this intervention took place in-service and as a continuation of their professional development, continuing professional development (CPD) was considered in the healthcare context. While CPD differs from one country and one context to the next (Sherman and Chappell, 2018: 1), there are certain elements of CPD that influence the success or limitations of the CPD. In the context of this research I will refer to CPD, with the understanding that this includes continuing medical education (CME) but is not limited to medical education. In the assessment of this CPD, the first two levels of Moore's CME Outcome Model were assessed: Participation and Satisfaction. It is expected that if a CPD programme has positive outcomes for a lower level, these could then influence positive outcomes for the higher levels.

Figure 7: Moore's CME Outcome Model

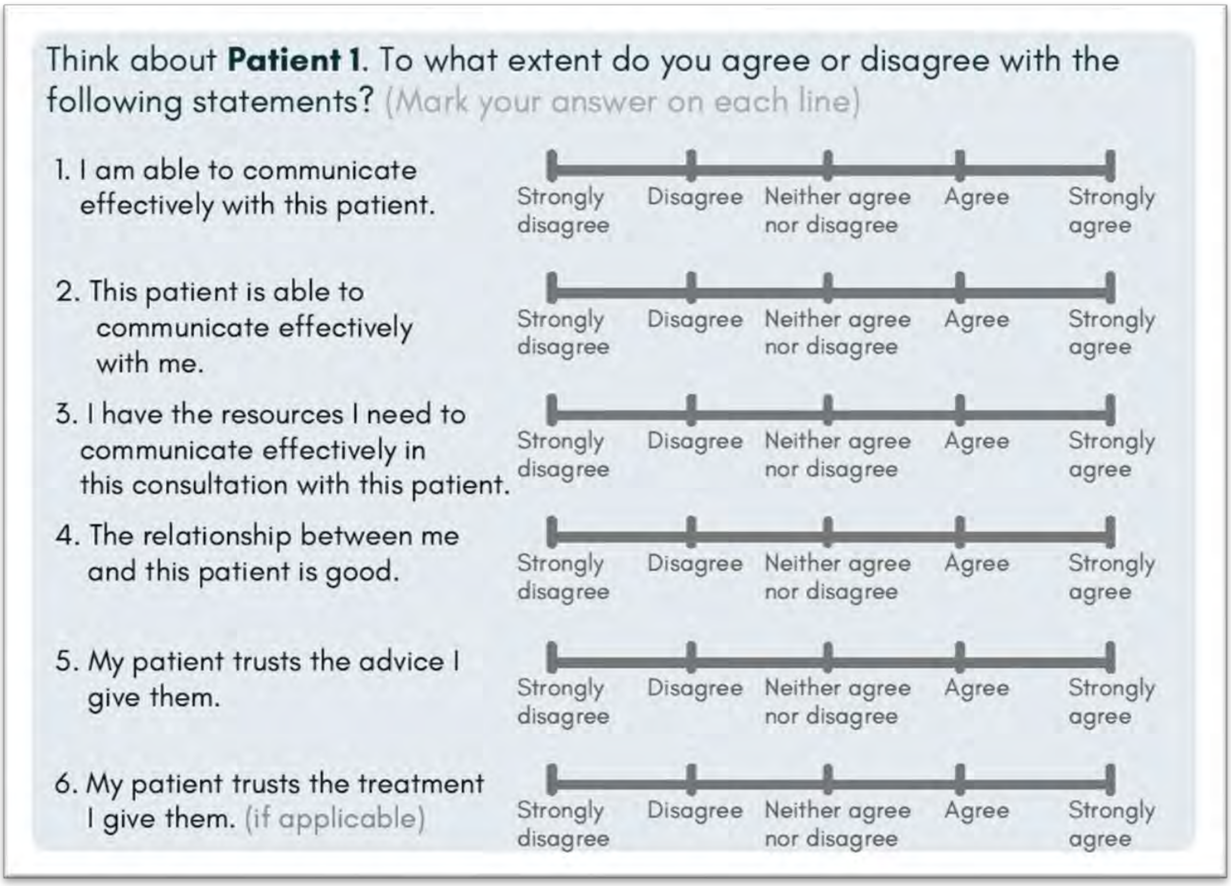
b) Measures

Questionnaires are often used in intervention studies to measure outcomes. Items in the questionnaire can be combined and considered together as a scale (Tymms, 2021b: 278), which can be used to measure something that is not evident at the surface level or from single questions, but rather by aggregating questions together (Tymms, 2021b: 282). In the case of this research the first questionnaire was conducted before the intervention group began using their resources and thus also served as a baseline assessment. In order for the assessment to be as brief as possible (to minimise the burden for participants and to increase the potential feasibility of the study), single questions with a Likert scale were used in the assessment.

The measures aimed to evaluate HCPs' self-reporting of their communication with their HCUs, their HCU's communication with them, the resources they have available for communication, the relationship between them and their HCU, and the trust their HCU has for the advice and treatment they give. The additional measures for the experimental group's T3 questionnaire assessed the HCPs' use of and satisfaction with the different resources.

Each HCP was asked to complete the measures for the past four HCUs for whom they provided an HIV/AIDS and/or TB consultation or treatment. Before completing the measures they were prompted to think about these last four HCUs and write down their initials.

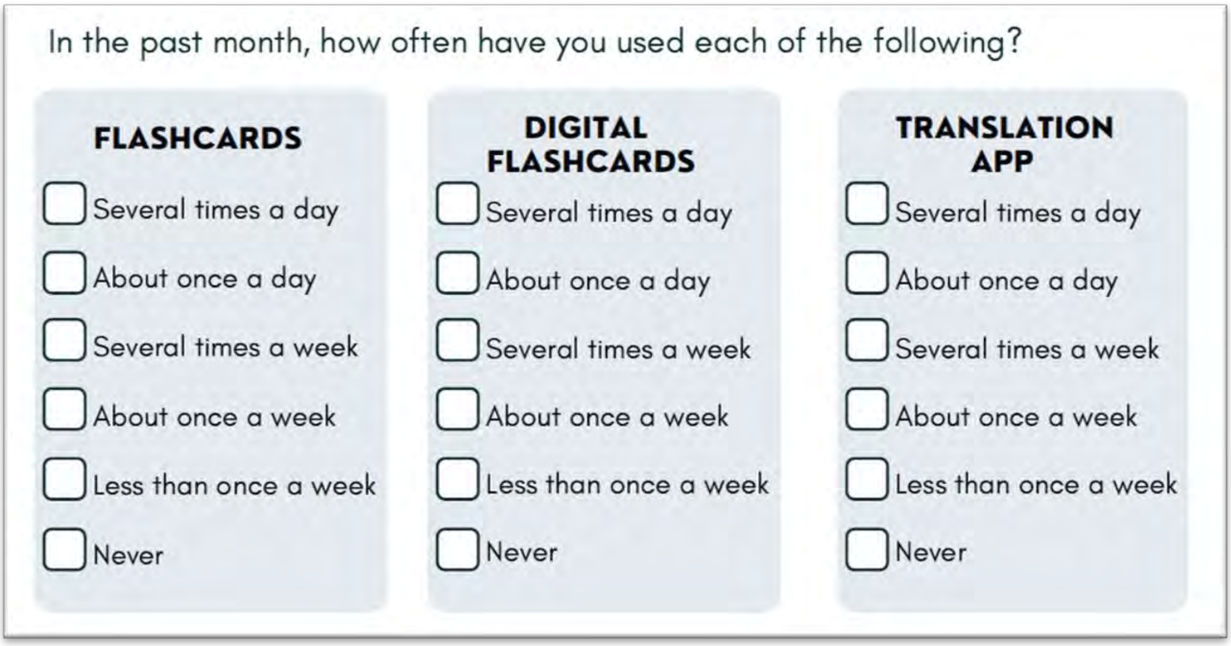
The measures for the T1-T3 questionnaire for the control group were as follows:



Think about **Patient 1**. To what extent do you agree or disagree with the following statements? (Mark your answer on each line)

1. I am able to communicate effectively with this patient.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
2. This patient is able to communicate effectively with me.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
3. I have the resources I need to communicate effectively in this consultation with this patient.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
4. The relationship between me and this patient is good.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
5. My patient trusts the advice I give them.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
6. My patient trusts the treatment I give them. (if applicable)
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree

The experimental group completed the same measures for T1 to T3, and in addition completed the following questionnaire on their use of the resources:



In the past month, how often have you used each of the following?

FLASHCARDS	DIGITAL FLASHCARDS	TRANSLATION APP
☐ Several times a day	☐ Several times a day	☐ Several times a day
☐ About once a day	☐ About once a day	☐ About once a day
☐ Several times a week	☐ Several times a week	☐ Several times a week
☐ About once a week	☐ About once a week	☐ About once a week
☐ Less than once a week	☐ Less than once a week	☐ Less than once a week
☐ Never	☐ Never	☐ Never

In some studies fidelity to treatment is assessed through observation, but as Tymms (2021a: 183) notes this can be expensive, and in this case it would also have required further ethical clearance. In this study fidelity to treatment, i.e. whether the participating HCPs used the proposed resources, was self-reported by the participants via the questionnaires. While still an acceptable means of assessing fidelity to treatment, Tymms (2021a: 183) rightly points out that the accuracy of self-reporting should be considered critically.

c) WhatsApp feedback group

The WhatsApp feedback group was conducted with the intervention group one month after the start of the intervention, at the time of the T2 measure. It was an asynchronous online focus group with the researcher posing questions and moderating.

Following the PAR methodology of this study, participants were involved in the choice of methods used for the focus group discussion. When signing up for the study, participants in the intervention group were informed that there would be an online focus group discussion, and could select to do this via Zoom or WhatsApp.

This feedback group was set up with the intention to serve as an easily accessible focus group discussion, as an alternative to an in-person focus group discussion (which could not be planned due to online changes for Covid measures) and as an alternative to a Zoom/video call group discussion (which can be inaccessible or difficult to access due to data costs, network service and loadshedding).

> Group interviews are a way to gather many opinions from individuals within a group setting but are largely didactic between an interviewer and each individual in the group. The distinguisher of focus groups is that they are *interactive*, the group opinion is at least as important as the individual opinion, and the group itself may take on a life of its own not anticipated or initiated by the researcher.
> (Gibbs, 2021: 240)

The WhatsApp focus group was intended to be interactive and give participants an opportunity to form opinions together about the resources, as well as to provide a peer learning opportunity where participants could share their experiences of how they had used the resources with each other. Focus groups can also facilitate change – positive or negative – as a result of participants' discussions and interactions with one another (Gibbs, 2021: 241). A focus group discussion of some kind was therefore in line with the aims of the study, as it gave the opportunity to merge feedback and further training in the most feasible way possible. As Gibbs (2021: 244) notes, however, "[t]he issues to consider when using distance methods for focus groups will be similar to those for traditional focus groups but will also involve new challenges for researchers". These are discussed in Chapter 7.

A side note about focus groups is that traditional focus groups can sometimes be more complex to interpret and analyse due to non-verbal responses and interactions (Gibbs, 2021: 241). While there are certainly many communicative elements to take into account when analysing a focus group, using WhatsApp as a means of communicating meant that all communication was clearly recorded, and participants' use of emojis also gave some recordable insights into non-verbal responses.

Participants were asked to give their feedback on how easy or difficult the resources had been to include in their practice, and they could choose whether to respond with voice notes or text messages. The participants were also encouraged to share their feedback on:

1. Any highlights or lowlights;
2. Their HCUs' responses to the resources;

3. Something they had figured out that they would like to share with others;
4. Other ways in which they thought the resources could be used;
5. Items that could be added to the resources; and
6. Any further support they might need within the scope of the *Healthy Talk* intervention.

d) Individual interviews

After completing the T3 questionnaires, participants in the intervention group were invited to participate in individual interviews to speak about their experiences of using the resources and participating in the study. Similarly following the PAR methodology, participants had the option to suggest alternative online means of participating in the feedback interviews. This resulted in the interviews being conducted via video call on Zoom, and via voice notes on WhatsApp.

The individual feedback interviews posed the following questions about the feasibility of the study:

1. Why did you choose to participate in the study?
2. What facilitated your participation in the study / what made it easy to participate in the study?
3. What barriers did you experience / what made it difficult to participate in the study?

The individual feedback interviews posed the following questions about the feasibility of the resources:

1. On your questionnaires you said you used X resource X often. Can you tell me a bit more about how you used it?
2. What effect do you think this resource had on your communication with your patient?
3. What effect do you think this resource had on your relationship with your patient?
4. What do you think was the most important or helpful thing about this resource?
5. What do you think should be changed about this resource?

2.4.7. Analysis of feasibility

a) Progression criteria

The suggested quantitative criteria for the study to meet in order to proceed from a pilot feasibility trial to an RCT are the following:

- Sample size as determined by a power analysis;
- Fidelity to treatment (i.e. use of the resources);
- Acceptability of the resources, as determined by ANOVA.

These criteria should be considered together with the qualitative analysis and accompanying recommendations.

b) Sample size

A power analysis was conducted prior to the study to determine the required sample size, where power is "the extent to which the sample size is sufficiently large to give a reasonable expectation of finding a statistically significant result." (Tymms, 2021a: 181). Because this study looks at the difference between the two groups (experimental condition and wait-list condition) at two timepoints, a repeated measures ANOVA for within-between interaction was used to measure the time by group interaction. The power analysis was conducted with the aim to be able to detect an effect size of .25, α set to 0.05, and power set to 0.8.

The required sample size for an RCT was calculated as follows using G*Power:
With power = .80 and α = .05, repeated measures Anova with n=45 in each group, enables detecting a small effect size difference (f = 0.15, equivalent to d = 0.3).
Each participating HCP were asked to complete the measures for the past four HCUs to which they provided a consultation or treatment for HIV/AIDS and/or TB. This means that for the 45 participants in each group (control and experimental groups), nine HCP participants were needed per group. As such, the required minimum sample size for the ancillary analysis was 18 HCPs. If this sample size is not attained and underpowered tests are done, this should be viewed with caution and as Eldridge et al. (2016 (b): 23) point out, "investigators should always point out this limitation to avoid misinterpretation of results". Furthermore:

> In RCTs evaluating the effect of an intervention, outcomes are usually measured on participants and therefore denominators are numbers of participants. However, because of the potential variety of objectives in a pilot trial, the denominators for

> measures that assess feasibility according to these objectives might be organisations, health practitioners, patients, or, in some cases, episodes or events.
> (Eldridge et al., 2016b: 21)

In the case of this pilot feasibility trial, the denominators are consultations, as reported by HCPs. However, for a definitive RCT the denominators would need to limit the potential for bias found in the same individuals self-reporting on numerous measures. As such, the definitive RCT could use self-reported measures from 45 individual HCPs or HCUs in each group, or measures from 45 consults in each group if these were measured independently (e.g. by observation).

c) *Fidelity to treatment*

Fidelity to treatment was self-reported by HCPs in the intervention group, as detailed in the measures. This analysis was conducted by calculating how many participants self-reported using each resource at the T2 and T3 assessments.

d) *Repeated measures ANOVA*

> The technique is called analysis of variance because the variance due to differences in performance is separated into variance that's due to differences between individuals *within* groups and variance due to differences *between* groups. Then, the two types of variance are compared with one another.
> (Salkind, 2008: 202)

When conducting a trial to measure a behavioural intervention, it is important that when the results are analysed they take into account the contextual reality that participants already differed from each other before the intervention, during the intervention and after the intervention. In the case of this research, the participants have different language proficiencies, different levels of professional medical experiences, different HCUs, and different work environments (to name some of the more obvious differences). To simply do a pre-test, roll out the intervention to all participants, and then conduct a post-test would likely show a difference from before and after the intervention, but it would not be possible to say with certainty that the difference that has been measured is due to the intervention. To check whether the difference is indeed due to the intervention, a control group is needed: a group of participants who do not receive the resources and training of the intervention, but complete the same pre- and post-tests as the experimental group. If, in this scenario, the experimental group showed greater pre- to post-test improvement than the control group, it would be possible to attribute that difference to the intervention. However, we could only attribute this to the intervention with certainty if the two groups were from the same sample with the same attributes. In the case of this intervention, where participating HCPs have so many differences in their contexts and their personal attributes, it is necessary to confirm whether the difference would still have occurred without the intervention or not. This can be done with an analysis of variance (ANOVA). Using ANOVA, it is possible to conduct tests to establish how much variability there is between the control and experimental groups, and compare it to how much variability there is within each group (Polit & Beck in Connelly 2021: 218). In a one-way repeated measures design, as is used for this study, there is variation between the time points at which each participant completed the measures, and between the participants themselves (Chan, 2021: 362). Given that we assessed participants at multiple time points, a repeated measures ANOVA was appropriate to analyse the results.

Following the eight steps outlined by Salkind (2008: 206–211), the analysis was run as follows:

1. Statement of the null and research hypotheses

The null hypothesis (Equation 1) is set for three time points, and shows that if the intervention did not make a difference, then this would be evidenced through no difference between the time points.

$$H_0: \mu_1 = \mu_2 = \mu_3$$

Equation 1

The research hypothesis (Equation 2) shows that if the intervention made a difference, then the measures collected at the three time points would differ from one another:

$$H_1: \bar{X}_1 \neq \bar{X}_2 \neq \bar{X}_3$$

Equation 2

2. Level of risk associated with the null hypothesis was set at alpha = .05, meaning that, on average, there is a less than 5% chance that the null hypothesis is correct.
3. Selection of the appropriate test statistic.

ANOVA can be used in one-way independent groups designs, factorial independent groups designs, one-way repeated measures designs, and mixed designs (Chan, 2021: 359). For the analysis of this trial a one-way repeated measures design was selected.

4. Calculation of the obtained value.

In this step the *F* ratio is calculated. In order to calculate the *F* ratio, it is first necessary that: the samples are independent of each other (e.g. not the same group of people tested at different times), that the variance within the control group is similar to the variance within the experimental group (i.e. the participants in one group differ from each other to a similar degree as the participants in the other group), and that the groups are both samples of a population with normal distribution (Connelly, 2021: 218).

5. Calculation of the critical value.

In this step the value needed to reject the null hypothesis is determined.

6. Comparison of the obtained value and the critical value.

Here the values from steps 4 and 5 are compared with each other.

7. and Step 8. A decision is made.

If the obtained value is greater than the critical value, then the null hypothesis is not accepted as there is indeed a difference between the values sufficient enough to attribute the difference to the intervention rather than to chance. If, however, the obtained value is not greater than the critical value, then even though it may appear that there are differences between the three time points, they are not sufficient to reject the null hypothesis (Salkind, 2008: 211). If the null hypothesis is true, i.e. if the intervention did not make a statistically measurable difference, then the means of both groups would be similar; if the *p* value is significant and the difference made by the intervention is statistically significant, this means that the difference between the mean of the control and experimental groups is large enough to be attributed to the intervention (Connelly, 2021: 218). If this is the case, it is then necessary to conduct post-hoc tests to make comparisons across the different variables of the groups.

The ancillary analysis of the resources should not be interpreted as hypothesis testing of the true effectiveness of the resources, in the way that one would conduct hypothesis testing for clinical outcomes. Indeed, hypothesis testing in pilot feasibility studies is cautioned against:

“Typically, any estimates of effect using participant outcomes as they are likely to be measured in the future definitive RCT would be reported as estimates with 95% confidence intervals without P values – because pilot trials are not powered for testing hypotheses about effectiveness.” (Eldridge et al., 2016b: 17). As such, the ancillary analysis should be seen as an analysis of HCPs support of the resources, or the acceptability of the resources to the HCPs, and their self-reported perceptions of effectiveness.

e) Codebook thematic analysis

Codebook thematic analysis was chosen to analyse the qualitative data from the pilot feasibility trial, because it allowed for the researcher to further explore the themes identified in the initial strands of the research, and in this way to position the qualitative findings of the pilot feasibility trial within the existing aims and research questions. Unlike reflexive thematic analysis, codebook thematic analysis begins with pre-determined themes (Braun et al., 2019: 849). In order to test or explore these themes, domain summaries are created by exploring the data in reference to the themes.

f) Other qualitative measures of feasibility

Feasibility was also considered in terms of participants’ consent, with fieldnotes informing the successes and challenges of attaining informed consent. Eldridge et al. (2016b: 13) note the importance of documenting the consent processes in a pilot feasibility trial as this can speak to the generalisability of the results, and to inform processes for scaling up the trial for an RCT while identifying aspects that might be difficult to implement in the future trial.

The number of potential participating sites is also detailed, with some details of the process noted. Similar to the importance of documenting the number of potential participants approached (see Eldridge et al., 2016b: 18), reporting on the consent and assent of sites during the recruitment process gives clarity on the external validity of the results, and to indicate the potential for recruitment of sites in the future RCT.

Where possible, notes were taken on losses to follow-up and exclusions. While this is important for interpreting generalisability in an RCT, it provides additional value in a pilot feasibility trial to give insights into the acceptability of the intervention (Eldridge et al., 2016b: 18), and to assist in limiting losses to follow-up where possible.

Finally, together with the recommendations following the pilot feasibility trial, the limitations of the trial are identified and discussed, noting which limitations could potentially be overcome in a future RCT and which likely could not be overcome (Eldridge et al., 2016b: 23). This speaks directly to the feasibility of the intervention.

2.5. Conclusion

This chapter has clarified the appropriacy of a mixed methods methodology for this interdisciplinary research. Drawing from different methodologies, this chapter has shown how PAR and a pilot feasibility trial are complimentary for the aims of this research. The methods of thematic analysis and ANOVA have been explained and the use of each has been detailed, elucidating the different types of data that each can work with, and the expected output of such data analyses. The practicalities of this research are framed within the theoretical perspectives which guide them, taking into account the importance of active participation from the study participants, the value of qualitative data both in creating and evaluating the intervention, and the scientific value and guidance imbued in this project through the structure of the pilot feasibility trial. The community-oriented focus of PAR ensures that all participants' voices are valued, and in so doing facilitates action that is most likely to have a long-term effect on the community in which the research is done. The use of mixed methods allows for these results to be further generalised to other similar communities, and also enables the rigorous analysis required to assess the overall success and shortfalls of the project and make clear recommendations for a potential future RCT. As such, this chapter has outlined the theory within which the data can be interpreted in the following chapters.

Chapter 5: Needs analyses

5.1. Introduction

The literature outlined in Chapter 2 illustrated the severity of South Africa's HIV/AIDS and TB epidemics, showed that a majority of healthcare consultations take place across language barriers, and described some strategies HCPs use to bridge language and communication barriers. The two empirical studies presented in this chapter confirm that communication and language barriers are indeed commonly faced; give further qualitative insights into such communication experiences and strategies; describe the ways in which HCPs have different approaches to navigate or minimise these barriers; and present HCPs' different opinions on what resources would be most useful for them in addressing these barriers. Using the methodology outlined in Chapter 4, the two studies presented in this chapter build upon the literature on communication barriers and strategies in the provision of HIV/AIDS and TB healthcare in South Africa broadly, and more specifically in the Eastern Cape.

This study addresses research questions 1 and 2, namely *How do HCPs and HCUs communicate when they are not fluent in the same language?* And *What communication resources and training are appropriate for the provision of HIV/AIDS and TB healthcare in South Africa?* This is done through the objectives of identifying the main communication problems experienced by HCPs as well as the communication strategies they use, with these strategies viewed (through the lens of Hulsman's (2009: 303) goal-oriented theory as problem-solving behaviour). This is done in preparation for Research Objective 3: *To create and implement communication resources and training to be used by healthcare professionals in the provision of HIV/AIDS and TB consultations.*

This chapter presents two studies that were conducted: the first was an online pilot study conducted with individual HCPs during the initial stages of South Africa's COVID-19 lockdown, which set out to explore the communication barriers experienced by HCPs in South Africa in the provision of HIV/AIDS and TB healthcare. After the completion of the first study, resources were sourced and compiled, and sites for the pilot feasibility trial were recruited. In preparation for the pilot feasibility trial, a second online study was conducted with potential participants of the pilot feasibility trial as a needs analysis and to gather feedback on the potential resources. These two studies are presented as separate according to the chronological order in which they were conducted, and while the studies and their respective discussions are presented independently, it should be remembered that, as practiced as part of PAR, each preceding step informs the next. The results of the second study were then used to finalise the pilot feasibility trial, which is described in Chapter 7.

5.2. Pilot needs analysis

A pilot descriptive study was conducted between August and October 2020. The aim was to do an explorative scoping review of HCPs working with HIV/AIDS and/or TB, focusing on communication strategies and unmet needs. Although the focus of this research is on HIV/AIDS and TB in the Eastern Cape, this pilot descriptive study was open to HCPs throughout South Africa. This was in response to restrictions imposed by the COVID-19 lockdown, which made in-person fieldwork unfeasible during that period. In order to attain a larger sample through snowball sampling, and conscious of the lockdown-related limitations, the descriptive study was made available to HCPs irrespective of their location within South Africa. This chapter gives a summary of the survey, after which the sample is described, the language proficiencies and barriers of the participants are detailed, the potential support for a communication app is confirmed, and the themes that emerged from the survey are discussed. This chapter concludes that the proposed intervention is well-suited to the unmet needs of this sample.

5.2.1. Aims of the needs analysis

This needs analysis focused on research questions 1 and 2. It aimed to ascertain to what extent HCPs experienced communication barriers, to explore how HCPs and HCUs communicate when they are not fluent in the same language (i.e. what problem-solving communication behaviours they employ), and to begin gathering ideas about what communication resources and training could be appropriate and feasible for HIV/AIDS and TB healthcare provision in the Eastern Cape, South Africa.

5.2.2. Methods

Participants were asked the following open-ended questions:

- Are there any specific concepts in your HIV/AIDS, TB and/or COVID-19 consultations that are difficult to communicate? If so, please provide details.
- Are there any specific terms or phrases in HIV/AIDS, TB or COVID-19 care that cause communication difficulties? If so, what are they?
- What are some strategies you use when you and your patient are not able to understand each other?

- Do you have any suggestions for resources that would make communication easier for you and your patients?

Using a reflexive thematic analysis (Braun et al., 2019), the following themes were identified from participants' responses: language barriers, key points of communication between HCP and HCU, and communication strategies. These themes are expounded on in the results section of this chapter.

5.2.3. Procedures and participants

This study was conducted online, using the SurveyMonkey platform. The survey consisted of: an information page describing the study, an informed consent page with opt-in consent to participate, several closed-ended, yes/no or checkbox questions about languages spoken, use of apps, job and workplace descriptions; Slider Scale questions about communication with HCUs; optional, open-ended questions exploring specific communication difficulties, strategies and suggestions; and options for follow-up communication. The SurveyMonkey inbuilt tools estimated a completion rate of 60% and an estimated completion time of 15 minutes to complete this survey.

This study was open to all healthcare professionals working in South Africa, if they provided healthcare services to people living with HIV/AIDS and/or TB.

This survey was primarily conducted using snowball sampling, with the addition of sharing the study publicly online. Some of the participants are people known by the researcher in a personal or professional capacity, and most of the participants are people with whom the researcher's contacts shared the survey. The survey was shared via WhatsApp, email, the researcher's personal social media profiles, and the social media profiles of the *Healthy Talk* project.

a) Sample description

The inclusion criteria for the survey was set by the question "Do you provide healthcare for people living with HIV/AIDS and/or TB?". Forty-one people selected to do the survey, of which 37 met this criterion. The four who did not meet this criterion were disqualified from the survey. Of the remaining 32, one opted out of the informed consent and was also disqualified from the survey. Thus 31 participants were included in this pilot scoping study. Not all surveys were completed in full, but all data from answered questions is included.

The participants were mostly occupational therapists (7; 28%), pharmacists (6; 24%), doctors (6; 24%), and also include physiotherapists (2; 8%), a nurse, a clinical psychologist, a pharmacist assistant and a medical intern (1 of each; 4% each). Two of the participants were currently studying while practising. The participants work in Gauteng (10; 40%), Eastern Cape (6; 24%), Free State (6; 24%), KwaZulu Natal (2; 8%) and Western Cape (1; 4%). No healthcare providers (HCPs) working in the Northern Cape, North West, Limpopo or Mpumalanga participated in this study. Most participants work at hospitals (18; 72%), with others working at clinics (6; 24%), pharmacies (4; 16%) and general practice (1; 4%). The majority of the participants worked in the public sector (21; 84%), two (8%) worked in the private sector, and two (8%) worked in both public and private sectors.

Most of the participants provided consultations between once a week and several times a day for HIV/AIDS, TB, and/or COVID-19. Twenty (80%) participants provided HIV/AIDS consultations at least once a week, 18 (72%) provided consultations for TB at least once a week, and 16 (64%) provided consultations for COVID-19 at least once a week. Only one (4%), three (12%) and six (24%) participants never provided consultations for HIV/AIDS, TB and COVID-19 respectively. These participants were however still included in the study, because they did still provide consultations for either HIV/AIDS and/or TB.

5.2.4. Results

a) Language proficiencies

Of the 29 participants who answered the question of home language, English was the most common home language (L1), followed by Afrikaans. Most of the participants (17; 58%) speak only English at home. Several are bilingual: four (14%) in English and Afrikaans, one (3%) in English and Shona, and one (3%) in English and isiXhosa. The remaining participants speak Afrikaans (4; 14%), isiXhosa and Sesotho at home. Most of the participants are able to have a conversation in a language other than their L1(s); however, several participants noted their limitations in these second languages (L2s) with qualifiers such as “very basic”, “basic [language]”, “partially”, “maybe”, “can dispense medication in [language] briefly”, “so so” and “with limited comprehension”. The qualifiers used in answering this question indicate limitations on the participants’ L2 knowledge, and may also indicate a lack of confidence or practice in these languages, or a proficiency suitable in certain settings but not in others. Second languages are as follows: 15 (52%) of the participants can have a conversation in Afrikaans, eight (28%) in English, three (10%) in isiXhosa, two (7%) in isiZulu, one (3%) each in Setswana, Sesotho and German, and four (14%) participants are not able to have a conversation in any language other than their L1.

Importantly, the majority of participants rely on or need assistance with communication, and even in the instances where such assistance is available in the form of an interpreter, communication is still difficult and ineffective. When asked how easy it is for the healthcare provider to communicate with their HCU without assistance from an interpreter, participants self-scored a mean and median of 5/10. When asked how easy the participants think it is for their HCUs to communicate with them without an interpreter, the average is 4/10. Participants have someone interpret in their consultations most commonly about once a week (9; 36%) or several times a week (6; 24%), while five (20%) have someone interpret once a month or several times a month, and five (20%) have someone interpret less than once a month or never. With assistance from an interpreter, participants scored the ease for them and their HCUs to communicate with each other at an average of 6/10.

b) An app

Many participants already use an app or apps in consultations with healthcare users: 12 (41%) use apps and 17 (59%) do not. Furthermore, if an app was available to assist healthcare providers communicate with HCUs who cannot speak English, 26 (90%) participants would use it, three (10%) might use it, and no participants said they would not use such an app. Of these participants, all use smartphones, with 19 (66%) using Android and ten (34%) using iOS operating systems.

Participants could indicate what type of communication app they would use, the far most popular choice was an app for COVID-19, HIV/AIDS and TB (24; 83%). Eight participants (28%) would use an app for HIV/AIDS and TB, followed by an app for HIV/AIDS, then equal interest in an app for TB, an app for COVID-19, and an app for COVID-19 and HIV/AIDS (5; 17% each), with least interest in an app specific to COVID-19 and TB (3; 10%).

c) Specific concepts

i. Language barriers

In these open-ended questions, several participants noted that the language differences between themselves and their HCUs caused communication barriers, effecting the communication from general understanding to very specific communication gaps. From the Sliding Scale questions about communication between HCPs and their HCUs it was clear that language barriers are present for many participants in their consultations. In the open-ended questions it was also clear that the participants are very aware of these language barriers, and participants working in a variety of settings also noted that some or many of their HCUs speak languages other than the official South African languages. Their perspectives on these language barriers differ, with some participants focused on the HCU's inability to speak English (e.g. "patients don't understand"), while others focused on their own inability to speak the HCU's L1. Similarly, some participants foregrounded the difficulties for them to communicate to the HCUs (e.g. "I find I have to use one or two words to describe what I would in a sentence in English"), others the difficulties HCUs have communicating with the HCPs, and some referred to both.

ii. Key points of communication

Overall, participants found communication barriers arose: when counselling their HCU, when prescribing or discussing medication, and from disease-specific concepts that use scientific words and medical jargon. The concepts of adherence and resistance were prominent in participants' responses, with an emphasis on how important these concepts are to communicate and the effects of miscommunication.

Participants noted their difficulties in counselling their HCUs ("I find it incredibly difficult to confidently counsel the patient on accurate information"), for example taking the HCU's history, explaining how a test will be done, discussing protective measures, explaining how to boost the immune system, and counselling the HCU on psycho-social issues. Language barriers make it difficult for the participants to ask their HCUs about their feelings/emotions and attitudes and to discuss their traditional customs and values, as well as difficulties relating to stigma. In these responses it is clear that participants are conscious of how language barriers limit them as HCPs speaking to their HCUs, limits their HCUs' ability to speak to them, and importantly limits both parties' ability to have a *conversation.* Participants also experienced difficulties or limitations in explaining dose frequency, how to use the treatment, and counselling their HCUs on importance of the medication, the reason for the prescription, and the side-effects of ARVs and TB medication.

Participants also found that medical terminology and jargon often caused communication barriers, and noted the following terms as specific examples of terms that are difficult to communicate: viral load, CD-4 count, XDR, MDR, peripheral neuropathy, disseminated or miliary, and virus. One participant also noted the difficulty they experienced with medical definitions and terminology in different South African languages. This perspective also illustrates an example of HCPs who focus on their limitations in speaking their HCU's L1.

Strongly linked to the above sub-themes, the most prominent concept throughout participants' responses to the open-ended questions was that of adherence and resistance. The terms themselves were noted as specific terms that often cause communication difficulties. Beyond the words themselves, the concepts were also described by participants as very important in their consultations, yet the necessary conversations about these topics were often challenging due to language barriers. Some disease-specific terms (like viral load and CD-4 count) were noted as important precisely because they facilitate understanding about the HCU's compliance with the prescribed medication and whether the treatment is effective. The elements the participants noted as important include the types of drug-resistant TB, finishing a course of antibiotics exactly as prescribed, following recommended exercises and activities (including how their disease affects them while doing this, and the importance of doing these exercises and activities), the necessity of naming or identifying barriers to adherence and discussing these, and most of all how treatment resistance can occur and why adherence is important. This participant emphasised how important adherence and understanding are: "Adherence to the HIV/TB medication and isolation in Covid is so so[10] important and if you can't get your HCU to fully understand that there is high risk of failure."

iii. Communication strategies

While the participants' ideas around key points of communication showed a lot of overlap, greater variation between participants was seen in the communication strategies they use and suggested. Some HCPs use strategies to communicate more clearly or check their HCU's understanding, for example repeating themselves, using gestures and visual and physical

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[10] Quoted as in original written feedback, with the second 'so' for emphasis.

cues, simplifying concepts into more easily understandable ideas, and asking the HCU if they understand. One participant noted the usefulness of metaphors when explaining the concept of antibiotic resistance using an example of Doom (insecticide spray) and cockroaches: “The doom kills everything except the strongest bugs like cockroaches, but then your house becomes full of the strongest bugs, and you need something stronger than doom.”

The other communication strategies used and suggested by the participants are: requesting someone to interpret, visual aids, language learning, and the use of an app. These are detailed below.

The most common strategy used by participants when they encounter language barriers is asking someone to interpret in the consultation. Participants report asking various people to interpret, from the pharmacy assistant, a nurse, a colleague, to “someone” who speaks the HCU’s L1. In one instance a participant would refer their HCU to another staff member who speaks the HCU’s L1. Many participants have responses that include the action of actively *requesting* assistance (e.g. “Asking nurses or other staff to help translate”), while other responses only include the act of *using* an interpreter (e.g. “I use nurses to communicate what I need”). The difference in these responses could reflect the HCP’s assumptions about the role of others, the visibility or invisibility of interpreting as a form of work, or the setup in their work environment (for example, if specific people are routinely called upon to interpret, or if finding someone to interpret requires seeking someone out).

The use of visual aids was the most prominent communication strategy suggested by participants. Many participants already use visual aids to help bridge communication barriers in their consultations, which includes drawing diagrams, drawing pictures, using pictures from the internet, using objects, and demonstrating on themselves. Some participants have created or printed their own visual aids (e.g. “I have printed some pamphlets with pictures explaining basic counselling tips on certain meds. Like take after food etc.”). Interestingly, only one participant reported using objects, which contrasts with the prominence of this strategy detailed in Penn & Watermeyer’s study (2018) that showed the use of objects in bridging communication barriers between pharmacists and healthcare users – this could be because other participants did not think to mention it, do not realise they do it, or indeed that most participants in this study do not use objects to assist communication. Many participants also recommended visual aids when asked what resources would be useful for them and their

HCUs, suggesting pictogram charts in different languages, pictographics, animations, and visual aids for treatments. The need for different languages to be included in visual resources was noted, and one participant pointed out the need to consider HCUs' levels of literacy when creating resources: "I work in a very rural area where a lot of older HCUs do struggle with reading and understanding. It would be so great to have a simple easy way for the HCU to explain themselves and ask questions."

Illustrating the different perspectives regarding upon whom the responsibility lies to improve HCP-HCU communication, one suggestion was made to "teach patients English at school". In contrast, some participants report using a few words of the patient's L1, or trying to learn the L1 of their HCUs: "I have learnt a handful of terms commonly used in counselling the patient e.g. Take 1 tablet three times a day. I have made a list of very basic translations and I use it during counselling... I struggle with pronunciation of some of the words so I would show the patient what I am trying to say." These two suggestions also illustrate different perspectives on the feasibility of different interventions. A suggestion was also made for an app to help people learn African languages, as the participant noted that Duolingo (a free, popular language learning app) does not have any South African languages.

Several participants use or have used Google translate in consultations with their HCUs, for example one participant uses it to play the yes/no questions out loud. The limitations of its usefulness in the South African/healthcare context are noted by another participant: "In desperate times I will use Google translate for basic words." Another concern was raised that "I find trying text to speech translation is slow, cumbersome and not always possible due to connectivity issues." When asked what communication resources may be helpful, a large number of participants suggested a translation app that uses (South) African languages, with many references to Google translate as an example. While this does show support for this project's idea to include an app as a communication tool, the prevalence of this suggestion may also be influenced by the questions about participants' current and potential use of apps in their consultations. When suggesting an app, some participants emphasised the need for such an app to be useful for the HCUs to explain themselves too. Suggestions for the app included an ability to translate commonly used phrases in counselling, and to include common yes/no questions. An information app was also suggested "with images and animations to explain concepts of infection, transmission, side effect management etc", and a phrasebook and a glossary were also suggested as an alternative to the translation app.

Considering the data gathered from these open-ended questions, it is clear that language barriers are a prominent feature of the participants' consultations, that certain concepts hold a lot of importance, and that an intervention should build upon strategies already being used (i.e. visual aids, interpreters and apps) and tailored to the South African context. What exactly this could look like is described in more detail in Chapter 6.

d) COVID-19

COVID-19 has impacted the average workday of all the participants: 72% said it has impacted their workday a lot or a great deal, and 28% were affected a little or a moderate amount. While the participants' responses did not suggest a need for Covid-specific resources above resources for HIV/AIDS and/or TB, there was overlap with the issues faced in communication about COVID-19 and communication about HIV/AIDS and TB. Specifically, difficulties in counselling HCUs about preventative measures and treatment adherence remained a common theme. This suggests that, while Covid-specific resources need not be created for this project, an awareness of the potential use of communication resources across different diseases would be beneficial. This ties in to the aforementioned recommendation made by Abdool Karim and Abdool Karim (2020: 367) to integrate the COVID-19 response with the already established HIV/AIDS and TB responses.

5.2.5. Discussion

This pilot study confirms what is reflected in the literature: language barriers cause communication gaps between healthcare providers and healthcare users (Anthonissen and Sobane, 2013; Crawford, 1999; Deumert, 2010; Kritzinger et al., 2014; Naidoo, 2014; Watermeyer and Penn, 2009). It is clear that HCPs are very aware of these barriers, and the most prominent features of their communication barriers are disease-specific terms and the concepts of adherence and resistance. The strategies used to address this vary among the HCPs and reflect their different perspectives. The tools suggested by this research, namely a communication app, visual aids, and resources to improve communication when working with interpreters, fit clearly with what HCPs have suggested here. Furthermore, the response to this online survey also suggest that the proposed intervention is feasible online. The proposed intervention is outlined in more detail in Chapter 6.

5.2.6. Limitations

Conducting a survey online has the potential to be impersonal and for targeted participants to feel distrustful or disinterested. By using snowball sampling an advantage was gained, as the people approached to participate already trusted the researcher or were interested in the research, and this trust and interest could be passed from participants known to the researcher, to participants known by other participants. A possible limitation of this, however, is that the demographic characteristics of the participants are more alike to those of the researcher and her circle of contacts than representative of HCPs in South Africa. Furthermore, the online nature of this survey limits this study to only include HCPs with internet access and at best an interest in and at the least the technical capabilities to participate in an online survey. The participants in this study should thus not be viewed as representative of all HCPs in South Africa, but rather as representative of a subset of HCPs in South Africa, as described in the descriptive data below.

5.3. Needs analysis for pilot feasibility trial

Preparatory data was collected from HCPs who will participate in the pilot feasibility trial. The purpose of this data collection was to gather feedback on the resources that could be provided to them in the pilot feasibility trial. This section gives a summary of the information provided and the feedback questionnaires and focus group schedule, after which the sample is described, themes are discussed, and resource-specific feedback is detailed.

5.3.1. Aims of the needs analysis

This needs analysis aimed to explore the communication resources and training that could be appropriate and feasible for HIV/AIDS and TB healthcare provision in the Eastern Cape, South Africa. Some ideas had been put together as a ‘resource preview pack’, and the appropriacy and feasibility was explored by gathering feedback from HCPs.

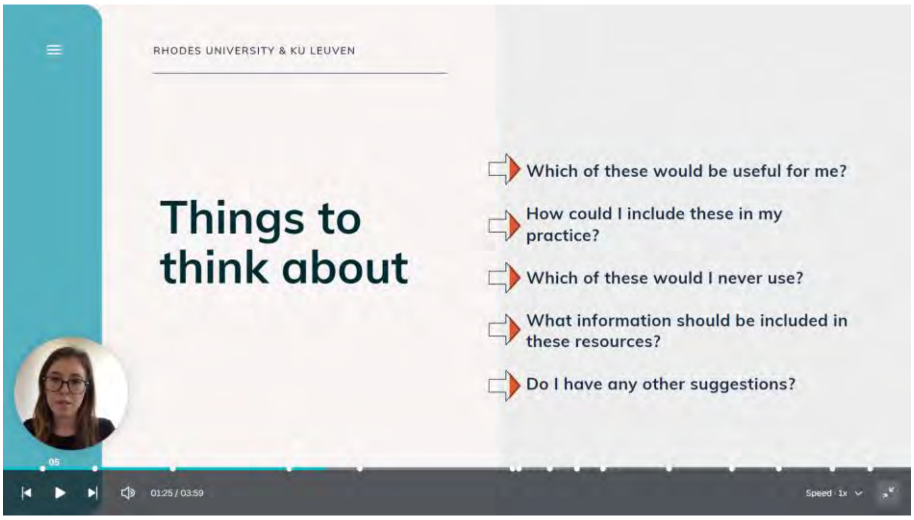
5.3.2. Description of the feedback study

The data collected in the initial pilot needs analysis was synthesised with recommendations from the literature (see Chapter 2), and relevant existing materials and training were scoped (see Chapter 6). Potential resources were then compiled into a ‘resource preview pack’, where they would be presented for feedback to HCPs who would potentially participate in the pilot feasibility trial.

5.3.3. Methods

Following the PAR nature of the study wherein participants also guided the methods used, data was collected in three ways: through informal interviews, questionnaires, and a focus group discussion. Due to the ongoing COVID-19 pandemic, and to further explore possibilities of using online means, all fieldwork in this study was conducted remotely and online.

The ‘resource preview pack’ was presented in a four-minute video presentation (Appendix 19) in the format of a narrated slide presentation created using Canva. In this video the study was introduced, and the proposed resources were explained. Before the resources were presented, participants were prompted to think about the following questions:



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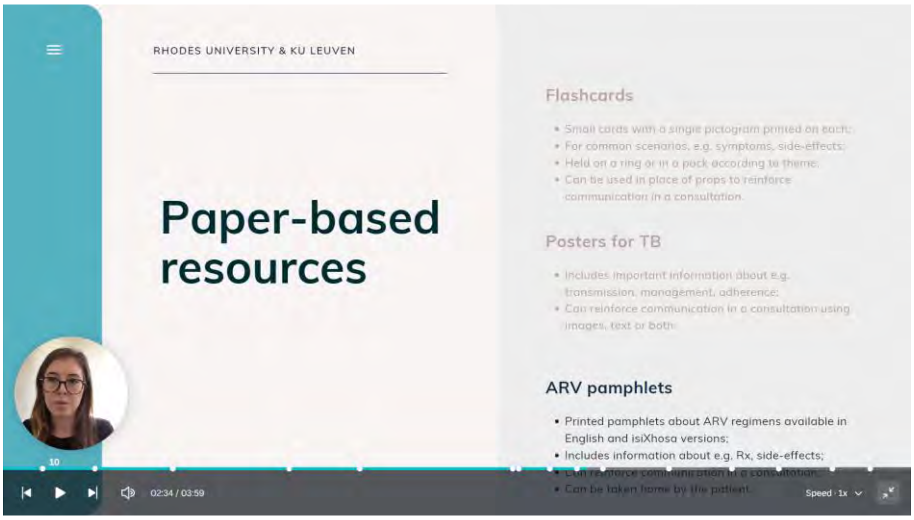
Things to think about

- Which of these would be useful for me?
- How could I include these in my practice?
- Which of these would I never use?
- What information should be included in these resources?
- Do I have any other suggestions?

Figure 8: Resource preview video (things to think about)

The resources were then presented, grouped together by their format, i.e., paper-based resources (flashcards, posters and pamphlets) and digital resources (translation and language learning apps):



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Paper-based resources

Flashcards

- Small cards with a single pictogram printed on each;
- For common scenarios, e.g. symptoms, side-effects;
- Held on a ring or in a pack according to theme;
- Can be used in place of props to reinforce communication in a consultation.

Posters for TB

- Includes important information about e.g. transmission, management, adherence;
- Can reinforce communication in a consultation using images, text or both.

ARV pamphlets

- Printed pamphlets about ARV regimens available in English and isiXhosa versions;
- Includes information about e.g. Rx, side-effects;
- Can reinforce communication in a consultation;
- Can be taken home by the patient.

Figure 9: Resource preview video (paper-based resources)

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Digital resources

Translation app

- Translates commonly used yes/no health questions into all 9 South African languages;
- Questions are arranged by theme for easy access;
- Can favourite most commonly used phrases;
- Favourited items are available offline.

Language learning app

- An app for learning isiXhosa on your phone;
- Teaches you healthcare-specific words and phrases in isiXhosa;
- You can progress at your own pace at times convenient for you.

Figure 10: Resource preview video (digital resources)

The methods of collecting feedback on the proposed resources are summarised as follows:

- **Introductory calls** were made to the participating Heads of Department, to explain the study, ascertain the interest for their department to participate in the needs analysis and pilot feasibility trial, and to answer any questions they may have had. Fieldnotes were taken during these introductory calls.
- In some cases, participants were asked to complete **printed questionnaires** with open-ended questions about the resources. The video presentation was shared with the HoDs and potential participants. After watching the video participating HCPs filled out these questionnaires. In line with the PAR approach, the printed questionnaires

were preferred by the participants over digital questionnaires, as they were more accustomed to filling out hardcopy questionnaires.

- In one case, a participant completed a **digital questionnaire.** This followed the same format as the printed questionnaires (a video presentation and a questionnaire about the resources presented), but was completed by digitally filling in the questionnaire using a PDF reader. Again, this was done using the PAR approach and according to the participant's preferences.
- At one site, a **focus group discussion** was held, as this was suggested by the Head of Department (HoD) as the team's preferred method over the questionnaires. For this discussion, the resources were presented to participants over Zoom, after which they gave feedback on what they would be likely to use, and what their considerations and concerns were.

5.3.4. Procedures and participants

a) Sample description

Purposive sampling was used. The sampling criteria for site selection was that sites must be in the Eastern Cape and provide HIV/AIDS and/or TB care, which was refined using convenience sampling to include tertiary or provincial hospitals and NGOs providing healthcare services. The sampling criteria for participants was that they must be healthcare professionals (HCPs) providing HIV/AIDS and/or TB care, and that they must experience communication barriers. Note that this did not limit the sampled participants by language group, as participants cited communication barriers both across and within languages.

For this phase of data collection five healthcare sites were included: three tertiary or provincial hospitals in a peri-urban area, and two clinic-style NGOs, one in a peri-urban area and one in a rural area. Ten participants were included, and consisted of: five doctors of internal medicine and infectious diseases, three with English as their home language (L1) and two with isiXhosa as their L1; three nurses, two with Afrikaans as their L1 and one with isiXhosa as their L1; one interpreter with isiXhosa as their L1; and one social worker with isiXhosa as their L1.

Following principles of participatory action research (PAR), participants played a role in guiding how the data was collected. Once permission for research had been granted by the healthcare site, the researcher spoke with the relevant Heads of Department (HoDs) and suggested ways which the data could be collected remotely, and asked the HoDs what would be most suitable for them. Some suggested that questionnaires be emailed to them, while another requested a focus group discussion via video call.

5.3.5. Results

a) Themes

Resources had been narrowed down by combining the data in the pilot study with reflections from the literature, and the resulting suggested resources were presented to participants in a video- or video-call presentation. Open-ended questions were asked in either informal interviews, questionnaires or a focus group discussion, in which participants were encouraged to speak about their communication strategies (or, their problem-solving communication behaviours), their communication needs (or, their goals), and their ideas about different types of resources (or, reflections on how resources could help achieve communication goals, considering their specific context and knowledge). Using reflective thematic analysis (Braun et al., 2017), the following main themes were identified:

b) Context-dependency

Participants explained that there is not, nor do they expect, any *one-size-fits-all* resources. They noted how different types of resources are needed for different topics, particularly for presenting information, compared to counselling, and compared to reinforcing information. The difference between resources needed by hospitals compared to clinics can largely be seen in terms of the HCUs seen at these different settings: while clinics see HCUs regularly and for testing, initiating treatment, routine check-ups, testing and medication, hospitals tend to see more HCUs who have more complex problems and/or who have defaulted on treatment. Attention was also drawn to the importance of the HCU's background, particularly their literacy levels (both language literacy and digital literacy), and their comfort with using digital media. This context-dependency clearly reflects the context-dependency highlighted by Hulsman (2009: 305).

c) Interaction

The importance of interaction in a consultation was stressed by participating HCPs. There was a strong preference for resources that facilitate interaction. In this way, it is important that any health communication resources are used to *reinforce*, and not to replace, communication between HCP and HCU. This reflects Hulsman's assertion that communication is interlinked with perceptual and behavioural skills (Hulsman, 2009: 303), and need to support each other in order to reach the communication goals.

d) Practicalities

The practicalities of the resources were considered by participating HCPs. One consideration was that resources need to be easy for one to take with them if they work at different sites, without printed resources getting destroyed or lost from being moved around. The practicalities relating to digital literacy, particularly pertaining to HCUs' digital literacy, were highlighted. Access to phones and internet was often brought up, but with different perspectives: some HCPs stated that phone-based resources were easy to use because everyone has a phone, while others noted how some HCUs rely on others in order to use a phone. Internet access was similar discussed, with some suggestions made for Wi-Fi to be made available at the healthcare site so that HCUs can access the resources, while others stating that access to Wi-Fi would be a barrier to using the resources. This further illustrates that communication goals are fluid, rather than fixed (Hulsman, 2009: 302).

5.3.6. Support for the resources

In addition to the general discussion about their communication strategies and needs, participating HCPs were asked to give specific feedback on each type of resource, particularly about how likely they would be to use each resource, and what would need to be taken into consideration for that resource. Participants' feedback is summarised below, and subsequently described per resource in further detail:

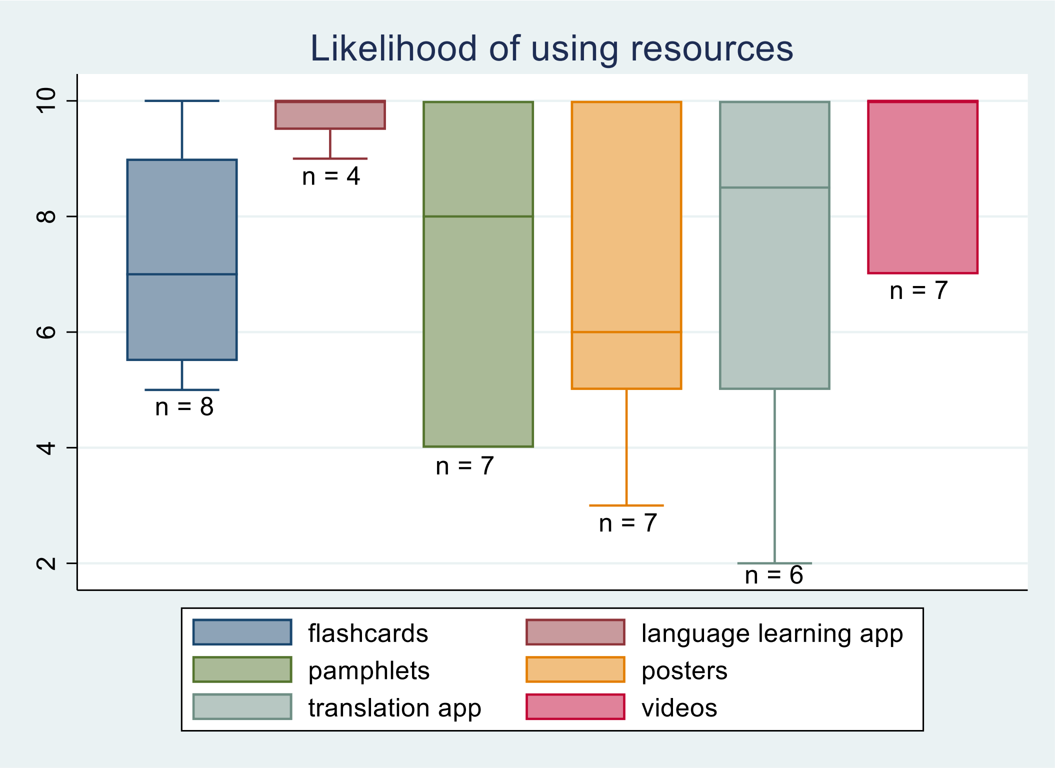

Table 2: Likelihood of using resources

a) Pamphlets

> *"I don't know if patients are going to go home and necessarily read pamphlets."*
> – Participant S4ID1

> *"There are patients that actually have no information at all about HIV and TB, and I think that those are the patients who might benefit from the pamphlet. Some patients have actually asked for them and we don't have any to give."*
> – Participant S4ID5

Support for pamphlets showed great variance, with some HCPs wondering whether HCUs would read them, and others pointing out that HCUs have, of their own accord, asked for pamphlets. A concern about pamphlets was that they are not interactive, and to mitigate this concern HCPs suggested that pamphlets are tied in with existing papers HCUs need to keep, for example their TB card.

b) Flashcards

> *"I think a flashcard as this sort of thing is that we've been shown is probably best from a counselling point of view because it's very interactive, you can have discussion point and go back and forth with pictograms and I think that's very useful."*
> – Participant S4ID3

The flashcards did not receive a lot of support in the questionnaires, while they received enthusiastic support in the focus groups. This could possibly be attributed to the more detailed explanation of the flashcards given in the focus group discussion compared with the briefer explanation given in the resource preview video that participants watched before completing the questionnaire.

c) Posters

> *"Within a clinic setting a poster might be useful, but the message that a poster can give is very limited because it's on a wall, there's no interaction, and it's there for a very specific, very broad, general message."*
> – Participant S4ID3

Posters with information about HIV/AIDS and TB were the least popular suggested resource. The reasons for this included that they are difficult to take from one site to another, and that their function is purely to present information and thus is not interactive.

d) Translation app

> *"Because there is no third person in a room, I think the patient will be able to be free to be open about their sickness."*
> – Participant S6I1

The suggestion of a translation app was very popular in the questionnaires, but less so in the focus group discussion. In the questionnaires, the privacy afforded by such an app was highlighted. In the focus group, concerns were shared about how interactive such an app may or may not be. Also in the focus group attention was drawn to digital literacy across generations, with HCPs noting that using digital resources such as this would probably work well with younger generations, while older generations may be unsure of it.

e) *Language learning app*

A healthcare-specific language learning app was explained in both the questionnaires and the focus group, but no one in the focus group discussion chose to discuss it. In the questionnaires HCPs showed strong support for such an app. The support for such an app by those who opted for questionnaires compared to those in the focus group could be attributed to the motivation for self-study or self-learning exhibited by the former group, as completing the questionnaire was a solo task done in one's own time.

f) *Videos*

> *"A few years ago, colleagues of mine did a video on the IUD, which is a contraception loop…. The patients loved it and we shared it everywhere. Eventually we were playing it on the TV in the waiting room and it was such a simple video, and it made a huge difference for the uptake on using that contraception"*
> – participant S4ID1.

The suggestion of videos was widely and strongly supported. In the focus group discussion on this was surprising, because the same participants who were hesitant about the language learning app and pamphlets because of their limited potential for interaction were enthusiastic about videos, which also have arguably limited potential for interaction. Possible reasons for this seeming inconsistency for which types of resources are preferred include:

1. A video requires less navigation and vulnerability for the HCP compared to a translation app. While the latter still requires some effort for interaction, interaction is not expected when watching a video and therefore the navigation and vulnerability is lessened.
2. Participants have more positive experiences of learning through videos than communicating with apps.
3. Watching a video could allow for increased interaction, as it could prompt questions or give both the HCU and HCP a common framework within which to speak about something.

When participants were asked what communication resources they were already using (if any), none of them cited the videos produced by the Department of Health.

5.3.7. Discussion

It has already been established that HCPs face language barriers in their consultations (Anthonissen and Sobane, 2013; Crawford, 1999; Deumert, 2010; Kritzinger et al.; Naidoo, 2014; Watermeyer and Penn, 2009). This study looked at what could be helpful for HCPs in these situations. This study gave insight into different individuals' perspectives on what could be helpful, and why some potential resources were preferred over others. This was considered in the framework of Hulsman's (2009) goal-oriented theory, which "may provide a common focus for both research and education in measuring, explaining and improving the HCP's behavior" (Hulsman, 2009: 302). While the feedback varied in some ways, there was a clear preference for the resources to be as interactive as possible. Interaction plays an important role in the biopsychosocial model, as it is necessary for HCPs and HCUs to communicate with each other about treatment and lifestyle, and interaction is a necessary element of a consultation in order for the HCP to not be dictatorial in the HCU's treatment. As such, the HCPs' preference for interactive resources may reflect a biopsychosocial model wherein HCPs affirm the importance of communication between HCPs and HCUs. In this way the participating HCPs also took ownership of the responsibility to facilitate optimal communication in their consultations, which contrasts with some of the views shared in the pilot needs analysis where some HCPs placed responsibility on the HCUs to speak English.

As could well be expected, HCPs' previous experience with resources informed their thoughts on how helpful a specific resource could be. While in some cases it seems that HCPs had had similar experiences, for example with posters, in the case of pamphlets we saw different amounts of interest because the HCPs had different experiences of the usefulness of pamphlets, and in the case of videos one HCP's very positive experience informed both her support for videos and the support of others in the focus group discussion as a result of the experience she shared. This is relevant to consider for a future RCT, or indeed any future study providing health communication resources: many HCPs have experience participating in studies, and/or have received resources from the Department of Health or other organisations, and their experiences with these vary. As such, any intervention research is not entering a neutral setting, and health communication researchers should be prepared to engage with HCPs on their previous experiences.

5.3.8. Limitations

While the use of PAR to inform the different methods used was a strength in terms of facilitating a participatory approach and gaining valuable insights, a limitation of this was that the different formats made the results across the different groups more complex to compare.

5.4. Conclusion

This pilot study confirms what is reflected in the literature discussed in Chapter 2: language barriers cause communication gaps between healthcare providers and healthcare users. It is clear that HCPs are very aware of these barriers, and the most prominent features of their communication barriers are disease-specific terms and the concepts of adherence and resistance. The strategies used to address this vary among the HCPs and reflect their different perspectives. The tools suggested by this research, namely a communication app, visual aids, and resources to improve communication when working with interpreters, fit clearly with what HCPs have suggested here. Furthermore, the response to the online survey also suggests that the proposed intervention is feasible online.

The needs analysis for the pilot feasibility trial showed that, just as a patient-centred approach requires each HCU to be considered as an individual with different needs and experiences, each HCP has their own needs and experiences in terms of the support they might need for health communication resources. This chapter also illustrated participating HCPs' patient-centred approaches as reflected in HCPs' claimed responsibility for ensuring optimal communication.

The findings from this chapter, particularly from the needs analysis for the pilot feasibility trial, were used to inform Chapter 6 in the selection and development of flashcards and an app. The match and mismatch of HCPs' suggestions for resources and how much they actually use them is detailed in Chapter 7 as part of the ancillary analysis of the pilot feasibility trial.

Chapter 6: Development of resources and training

6.1. Introduction

The intervention implemented and evaluated for this project consisted of a pilot feasibility trial of health communication resources, referred to here as the *Healthy Talk* intervention. This chapter provides details of the *Healthy Talk* intervention, particularly the resources considered and included, and the development and provision of health communication training. This chapter has a pragmatic rather than theoretical focus, and is included here in order to make this research replicable in order to extend its real-world impact, and to further test and develop the theories developed through this action research.

The literature detailed in Chapter 2 has shown that South Africa is in many ways at the forefront of the HIV/AIDS and TB epidemics, necessitating these diseases be included in interventions to improve public health. Poor medicines adherence plays a significant role (Department of Health, 2015: 18) and is hampered by HCUs' poor understanding of their disease, treatment and prevention (Penn and Watermeyer, 2018: 33). South Africa has 11 official languages, and despite policies aimed at ensuring that everyone can access healthcare services in an official language they understand, the reality is that a large proportion of healthcare consultations are conducted across language barriers (reported to be up to 80% by Penn in Haricharan et al. (2013: 58)). As such, the focus of this research is the issue of health communication, with the aim to equip HCPs with tools and knowledge to better communicate across language barriers in HIV/AIDS and TB consultations. Health communication courses are included in university healthcare degrees, but the depth and intensity of these courses differs across institutions (e.g. Penn and Watermeyer, 2018: 232). As it stands, there is still minimal, informal on-site language training for healthcare professionals in the dominant languages of HCUs who form significant majorities in particular provinces and metros (e.g. Crawford 1999), although this type of training is preferred by many healthcare students to university-level training (Penn et al. in Penn and Watermeyer, 2018: 327).

The primary means of minimising communication barriers is through interpreting, which is usually done on an ad-hoc basis by informal interpreters (Anthonissen and Sobane, 2013: 268; Crawford, 1999: 29; Deumert, 2010: 58–59; Kilian et al., 2014: 160). While it is often the most practical option, this model of communication is far from ideal: interpreting is often hindered by factors such as the interpreter not having a medical background (Anthonissen and Sobane, 2013: 269), the challenge of making medical discussion accessible to laypeople

(Deumert, 2010: 59), the unclear role of the interpreter (Penn and Watermeyer, 2018: 176), and concerns of confidentiality (Penn and Watermeyer, 2018: 177).

Apart from interpreting, useful tools to aid communication include visual aids such as props (e.g. Watermeyer and Penn, 2009), and pictograms (e.g. Dowse 2009). The symbols, icons, and complexity of such visual materials need to be relevant to the HCUs' culture, context, and literacy or education level (Penn and Watermeyer, 2018: 216; Dowse, 2009: 157). Pamphlets have had mixed successes, with the visual communication of the printed materials being an important influencing element (e.g. Anthonissen and Sobane, 2013, and Dowse 2009). Pamphlets are often text-heavy (when provided in English or in healthcare users' home language), resulting in limited uptake and usefulness; those that have proved most useful are pamphlets that are relevant to healthcare users' contexts, cultures and literacy levels.

Other recommended communication strategies include: the use of concept checking questions, for example verifying HCU's comprehension by asking them to demonstrate their understanding (Watermeyer and Penn, 2009: 211); cultural awareness and awareness of the HCU's perspective (Kagawa-Singer and Kassim-Lakha 2003, p. 582); and including open-ended language-related question in the opening sequence in a consultation (Deumert, 2010: 57).

The pilot questionnaire study conducted with HCPs throughout South Africa, as detailed in Chapters 5 and 6, gave insights into commonly-faced communication barriers, the strategies they use to minimise these barriers, and their suggestions for resources to support this. The majority of participants rely on or need assistance with communication, and their responses reflected the literature: most participants had someone interpret for them once or several times a week, and even with assistance from an (informal) interpreter, communication is still difficult and ineffective. There was strong support for communication resources such as an app and visual aids, and it was noted that these resources should cover medication, counselling, and adherence and resistance, using the healthcare user's language. Resources based on these suggestions were compiled into a 'resource preview pack' and shared with HCPs who provide HIV/AIDS and/or TB care in the Eastern Cape, and the feedback, also detailed in Chapters 5 and 6, showed strong support for a translation app, flashcards and videos, and mixed support for pamphlets. An important consideration for all of the resources is how interactive they are, and it was acknowledged that communication resources cannot replace interpersonal communication, and should rather be seen as supportive of existing communication.

This chapter gives an overview of the resource preview pack that was provided to HCPs before the pilot feasibility study began, and summarises which resources were identified as most useful and feasible. The chapter then outlines the resources that were considered to support communication between HCPs and healthcare users, and provides details about each resource that was chosen, developed or adapted for the *Healthy Talk* intervention. The training that accompanied the resources is described, with attention given to the participatory action research (PAR) methodology and how it informed the ways in which the training was conducted with participants. The findings of the pilot feasibility study, as detailed in Chapters 5 and 6, are the results of the implementation of the resources and training presented in this chapter.

6.2. Resource preview pack

A 'resource preview pack' was created by drawing on recommendations from the literature and findings from the pilot questionnaire. Another inclusion criterion was feasibility, which was considered in terms of feasibility of creation/adaptation and feasibility of use by HCPs.

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MAY 2021

HEALTHCARE COMMUNICATION:
Resources and training for HIV/AIDS and TB communication

HEALTHY TALK
BRIDGING COMMUNICATION GAPS IN HEALTHCARE

Presentation outline

- Introduction to the project
- Project timeline
- Questions about resources
- Paper-based resources
- Digital resources
- Training
- Questionnaires

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HEALTHCARE COMMUNICATION:
Resources and training

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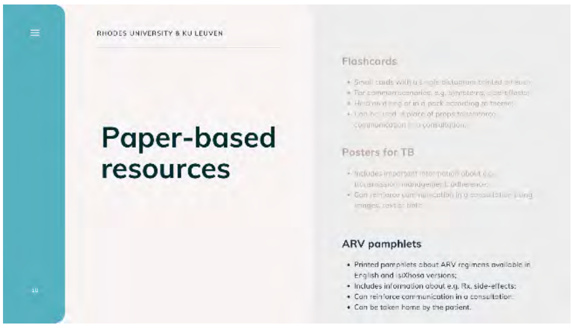
Things to think about

- Which of these would be useful for me?
- How could I include these in my practice?
- Which of these would I never use?
- What information should be included in these resources?
- Do I have any other suggestions?



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Paper-based resources

Flashcards

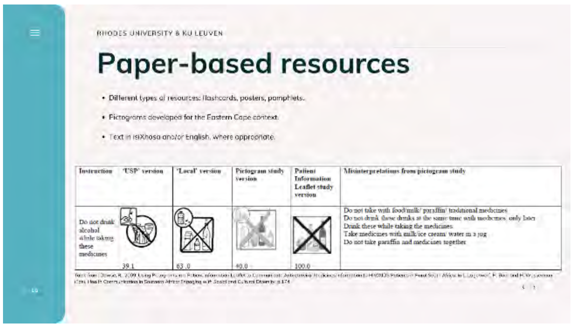
- Small cards with a single pictogram printed on each;
- For common scenarios, e.g. symptoms, side-effects;
- Held in a ring or in a pack according to theme;
- Can be used in place of props to reinforce communication in a consultation.

Posters for TB

- Includes important information about e.g. transmission, management, adherence;
- Can reinforce communication in a consultation using images, text or both.

ARV pamphlets

- Printed pamphlets about ARV regimens available in English and isiXhosa versions;
- Includes information about e.g. Rx, side-effects;
- Can reinforce communication in a consultation;
- Can be taken home by the patient.



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Paper-based resources

- Different types of resources: flashcards, posters, pamphlets.
- Pictograms developed for the Eastern Cape context.
- Text in isiXhosa and/or English, where appropriate.

Instruction	'USP' version	'Local' version	Pictogram study version	Patient Information Leaflet study version	Misinterpretations from pictogram study
Do not drink alcohol while taking these medicines	39.1	63.0	40.0	100.0	Do not take with food/milk/ paraffin/ traditional medicines Do not drink these drinks at the same time with medicines, only later Drink these while taking the medicines Take medicines with milk/ice cream/ water in a jug Do not take paraffin and medicines together

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Digital resources

Translation app

- Translates commonly used yes/no health questions into all 9 South African languages;
- Questions are arranged by theme for easy access;
- Can favourite most commonly used phrases;
- Favourited items are available offline.

Language learning app

- An app for learning isiXhosa on your phone;
- Teaches you healthcare-specific words and phrases in isiXhosa;
- You can progress at your own pace at times convenient for you.

Figure 11: Extracts from resource preview pack

The resource preview pack included an overview of the following:

- AwezaMed app
- ARV pamphlets
- TB poster
- Flashcards
- Language learning app

This resource preview pack was shared with HCPs who would participate in the pilot feasibility study, and feedback was collected to inform how to refine the resources for inclusion in this study. Following the PAR methodology of this study this was done in ways preferred by the participants: some received it as a video (Appendix 19) with a print-out questionnaire (Appendix 14) to be completed, and others received it as a presentation (Appendix 20) followed by a focus group discussion (via Zoom) (Appendix 15).

6.3. Resource development

The resources for this intervention were selected based on the feedback from the resource preview pack (as detailed in the needs analyses in Chapter 5), together with considerations of each resource's feasibility in terms of its creation or adaptation by the researcher, and feasibility of its use by the targeted HCPs. The resources that were selected for the *Healthy Talk* intervention are:

- AwezaMed app
- Flashcards (hardcopy)
- Flashcards (digital)
- Videos

The purpose and development or adaptation of each selected resource is described below.

6.3.1. Translation app

A translation app was identified as a useful communication resource in the pilot questionnaire study, and this was confirmed in the responses to the resource preview pack.

a) Identified resources

The following translation apps were identified:

i. Apps for speech and communication challenges

There are several text-to-speech or image-to-speech apps for people with speech or communication challenges, such as aphasia and autism spectrum disorder. These apps do not have translation capacities and are mostly in English, with support for other international languages (particularly Spanish), but not for South African languages.

ii. AwezaMed

AwezaMed (https://aweza.co.za/awezamed/) is a text-to-speech app for HCPs for eliciting yes/no answers from HCUs. It provides translations from English to all official South African languages. This app was selected as a resource to provide to HCPs in the pilot feasibility study and is described in more detail below.

iii. DeepL

DeepL (https://www.deepl.com/en/translator) uses machine translation and labels itself as "The world's most accurate translator" (deepl.com, 2020). It is available for 26 languages, not one of which is a language indigenous to the African continent.

iv. Google Translate

A commonly used and easily accessible translation tool, several HCPs reported using Google Translate (https://translate.google.com/) to assist their communication with healthcare users. However, as reported by these HCPs and literature, Google Translate is inaccurate and unreliable for South African languages in the healthcare context, with Patil and Davies (2014: 2) finding Google Translate has only 57.7% accuracy for medical phrase translations, with a bias towards Western European languages.

v. Mobile Translate MD

Mobile Translate MD (https://play.google.com/store/apps/details?id=nfs.mobiletranslatemd&hl=en&gl=US) is a medical translation phrasebook that supports translations from English to Afrikaans, French, isiXhosa, isiZulu and Spanish. Text-to-speech is supported for French and Spanish, but not for the South African languages, which have only a text-to-text translation that needs to be read out loud by the HCP or shown to the healthcare user to read the translation themselves. The phrases included are comprehensive, but are all flat utterances and require time navigating through the menus.

vi. Universal Doctor

Several text-to-speech apps for HCPs, including *Universal Doctor Speaker, Universal Nurses, Refugee Speaker,* and *Universal Pharmacist* (https://www.universaldoctor.com/). These apps are intuitive to use and comprehensive in nature; however, the only languages included from the African continent are Moroccan Arabic and Somali, and they do not include any indigenous South African languages.

b) Selected resource

i. AwezaMed App

The AwezaMed app is available for Android and iOS smartphones. It is a healthcare-specific translation app that translates text to speech, as well as speech to speech through automatic speech recognition and machine translation. Any utterance on the app can be clicked on and the text is translated both in text and speech forms, while only utterances that are already in the app can be recognised by its automatic speech recognition (Wilken and van Niekerk, 2020: 9). For the purpose of this research, HCPs were encouraged to use the text-to-speech functionality.

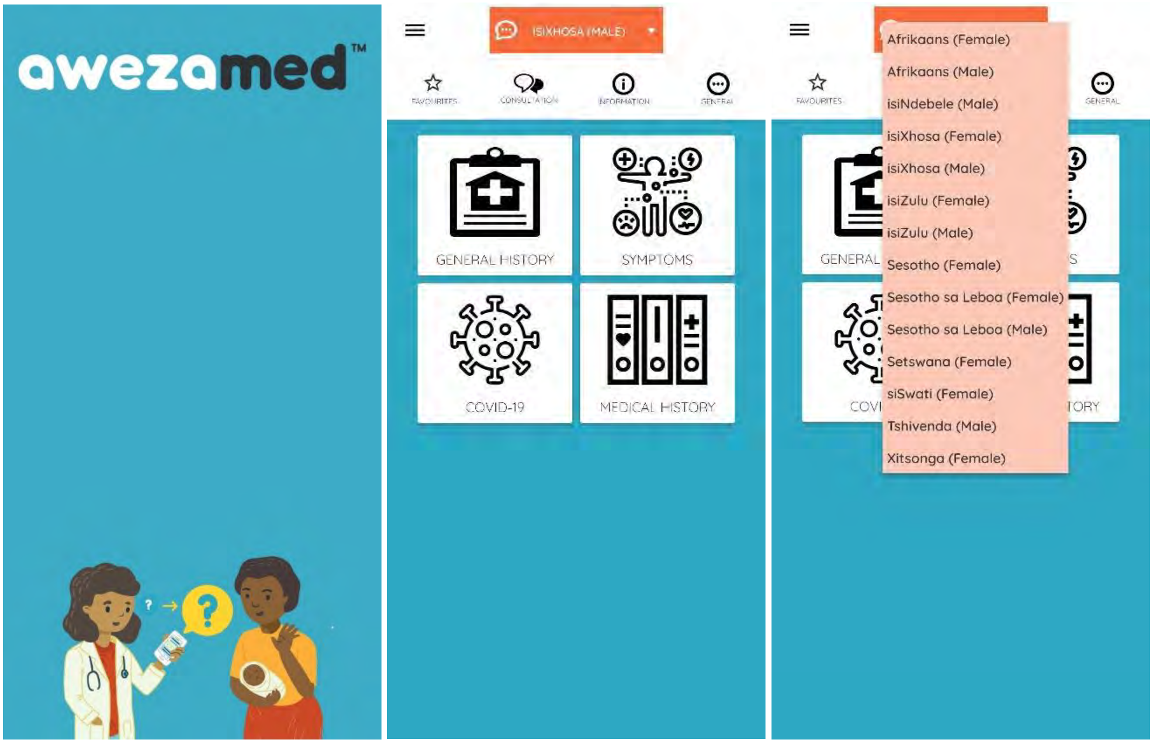
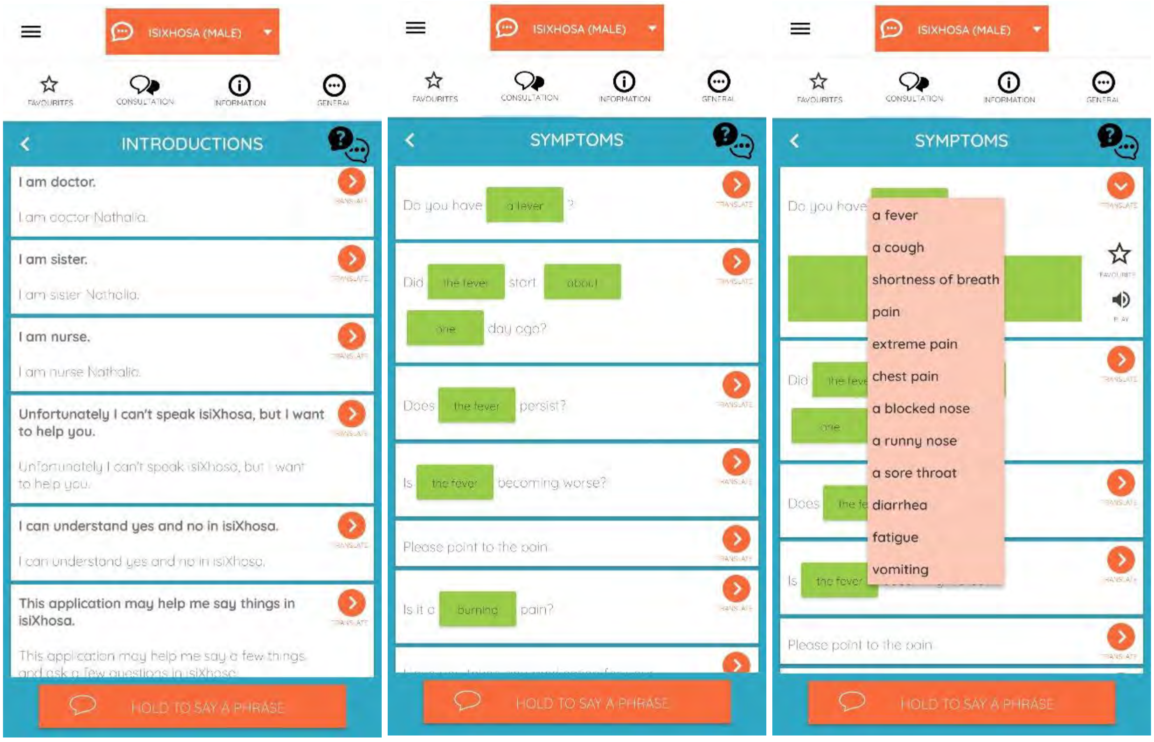


Figure 12: Screenshots of AwezaMed app

The default input and display are in English, and it provides translations to the other ten official South African languages, with options for a male or female voice for four of these languages.

The app is divided into different sections: GENERAL, which includes introductions and instructions; INFORMATION, which includes disease-specific information; CONSULTATION, which includes general history, symptoms, COVID-19 and medical history; and FAVOURITES, where frequently-used phrases (selected by the user) can be saved for easy access.



I am doctor.

I am doctor Nathalia.

I am sister.

I am sister Nathalia.

I am nurse.

I am nurse Nathalia.

Unfortunately I can't speak isiXhosa, but I want to help you.

Unfortunately I can't speak isiXhosa, but I want to help you.

I can understand yes and no in isiXhosa.

I can understand yes and no in isiXhosa.

This application may help me say things in isiXhosa.

This application may help me say a few things and ask a few questions in isiXhosa.

Do you have a fever ?

Did the fever start about one day ago?

Does the fever persist?

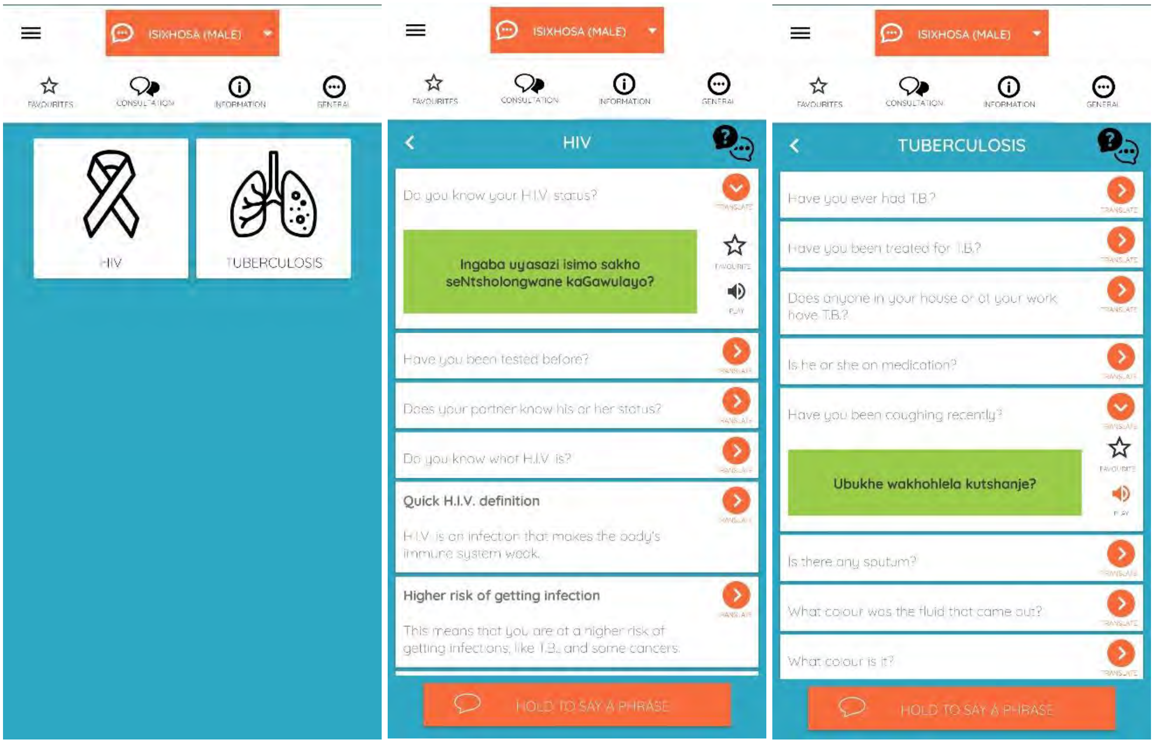
Is the fever becoming worse?

Please point to the pain

Is it a burning pain?

Figure 13: Screenshots of AwezaMed app

The HCP can see the sentence in the target language (TL) by clicking the TRANSLATE button. They may choose to read the sentence themselves, or click PLAY to play the translated audio of the selected sentence. Phrases that include green-coloured boxes of text are dynamic utterances: the text box can be clicked on to open a drop-down menu, thus reducing time spent finding a phrase.



HIV

Do you know your H.I.V. status?

Ingaba uyasazi isimo sakho seNtsholongwane kaGawulayo?

Have you been tested before?

Does your partner know his or her status?

Do you know what H.I.V. is?

Quick H.I.V. definition

H.I.V. is an infection that makes the body's immune system weak.

Higher risk of getting infection

This means that you are at a higher risk of getting infections, like T.B., and some cancers.

TUBERCULOSIS

Have you ever had T.B.?

Have you been treated for T.B.?

Does anyone in your house or at your work have T.B.?

Is he or she on medication?

Have you been coughing recently?

Ubukhe wakhohlela kutshanje?

Is there any sputum?

What colour was the fluid that came out?

What colour is it?

Figure 14: Screenshots of AwezaMed app

The AwezaMed app also includes sections about HIV/AIDS and TB specifically. These sections include questions commonly used in HIV/AIDS and TB consultations, as well as information covering topics such as testing, medication, transmission, prevention, and support.

All phrases are yes/no questions or statements to give information or instructions. In this way the app places the HCP as the primary communicator in a consultation. All flat utterances (i.e. phrases that cannot be changed) are available to see and read offline, and while the text-to-speech function requires an internet connection the first time each phrase is used, each utterance is downloaded onto the user's device once it is played (Wilken and van Niekerk, 2020: 8). The offline accessibility of the app allows HCPs with limited network connection or data availability to use it.

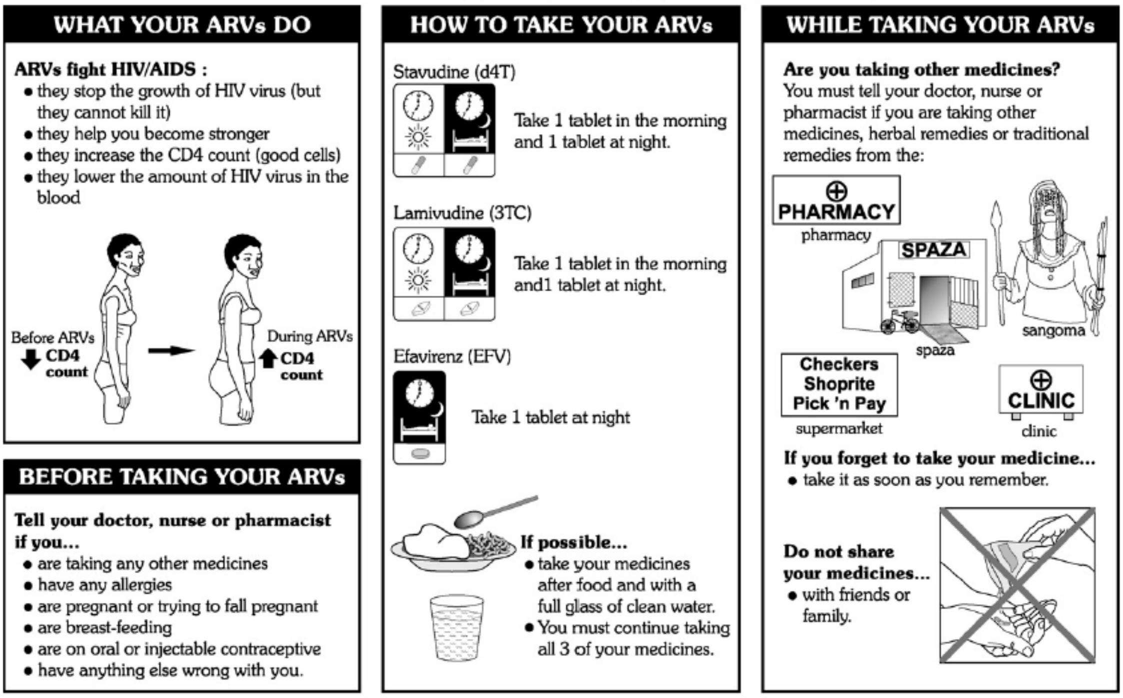
The app has already been validated by a heuristic evaluation, user testing and real-world usage. The heuristic evaluation scored the usability of the app 8.01/10 (Wilken and van Niekerk, 2020: 21). The user testing and real-world usage found that the app was not sufficient to replace human-to-human conversation, including conversation facilitated by an interpreter; however, when an interpreter was not available the HCPs in the evaluation found the app helpful (Wilken and van Niekerk, 2020: 16). Some HCPs reflected that the app would be helpful for them to learn isiXhosa (Wilken and van Niekerk, 2020: 17). It should be noted that the user testing and real-world usage was limited by COVID-19 lockdown restrictions and availability of participants, and so some of the feedback is anecdotal rather than representative of a larger sample.

In the pilot questionnaire study and feedback on the resource preview pack it was found that some HCPs in this intervention are interested in learning their HCUs' L1. While there was not enough interest to warrant the inclusion of a language learning app, there is the possibility for HCPs to acquire certain key phrases in the TL through the use of the AwezaMed app.

6.3.2. Flashcards

When scoping for health communication resources, no literature or existing resources included the use of flashcards. Rather, the idea for using flashcards was a combination of the use of props (as described in Penn and Watermeyer,2018) and the ability for meaning to be communicated through pictograms (as described in Dowse,2009). It was thus decided to create flashcards using the pictograms created by Dowse, as the pictograms were all developed to be appropriate for the South African context, and they were tested specifically with healthcare users in the Eastern Cape where they were found to be more clearly understood than their ubiquitous USP (United States Pharmacopeia) counterparts. Therefore it was not necessary to assess the quality or appropriacy of the pictograms used in the flashcards, making it possible to test the delivery format (i.e. flashcards) directly.

Some examples of the pictograms and their existing use are as follows:



WHAT YOUR ARVs DO

ARVs fight HIV/AIDS :
- they stop the growth of HIV virus (but they cannot kill it)
- they help you become stronger
- they increase the CD4 count (good cells)
- they lower the amount of HIV virus in the blood

Before ARVs ↓ CD4 count

During ARVs ↑ CD4 count

BEFORE TAKING YOUR ARVs

Tell your doctor, nurse or pharmacist if you…
- are taking any other medicines
- have any allergies
- are pregnant or trying to fall pregnant
- are breast-feeding
- are on oral or injectable contraceptive
- have anything else wrong with you.

HOW TO TAKE YOUR ARVs

Stavudine (d4T)

Take 1 tablet in the morning and 1 tablet at night.

Lamivudine (3TC)

Take 1 tablet in the morning and1 tablet at night.

Efavirenz (EFV)

Take 1 tablet at night

If possible…
- take your medicines after food and with a full glass of clean water.
- You must continue taking all 3 of your medicines.

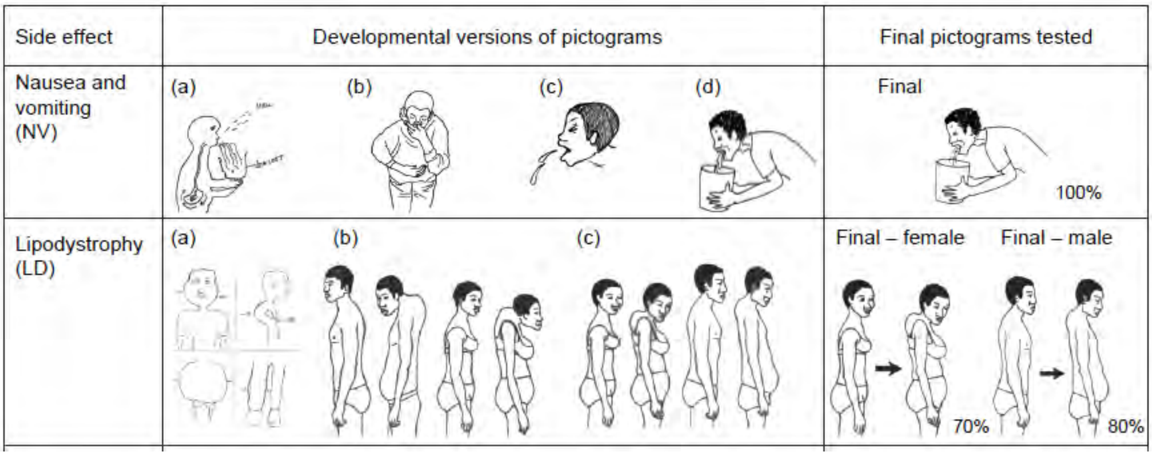
WHILE TAKING YOUR ARVs

Are you taking other medicines?
You must tell your doctor, nurse or pharmacist if you are taking other medicines, herbal remedies or traditional remedies from the:

If you forget to take your medicine…
- take it as soon as you remember.

Do not share your medicines…
- with friends or family.

Figure 15: Extract from ARV HCU information leaflet (Dowse, Ramela and Browne, 2011: 510)



Side effect	Developmental versions of pictograms	Final pictograms tested
Nausea and vomiting (NV)	(a) (b) (c) (d)	Final 100%
Lipodystrophy (LD)	(a) (b) (c)	Final – female 70% Final – male 80%

Figure 16: Pictograms of ARV side-effects (Dowse, Ramela, Barford & Browne, 2010: 218)

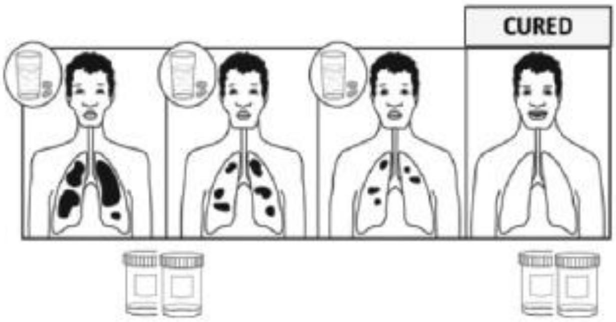


Figure 17: Image from TB booklet (Okeyo & Dowse, 2018: 3)

The pictograms were divided into the following sets:

- Symptoms and side-effects
- Medication
- Tuberculosis
- Miscellaneous

Words or short phrases to describe the pictogram were also included in English and isiXhosa in the development of the flashcards.

Flashcards were provided to HCPs in two formats: hardcopy and softcopy. The hardcopy flashcards were printed out on business card-sized cardboard, laminated, and grouped together on keyrings according to theme.

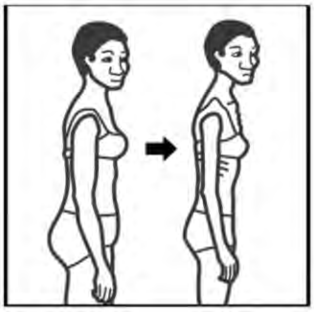
The digital flashcards consisted of the same pictograms in the same groupings, but were made available so that HCPs could show them on their cellphone. They could be downloaded by scanning a QR code in the communication manual or sent via WhatsApp.

Examples of flashcards in each set are shown below:

a) Symptoms and side-effects

rash

ukuba nerhashalala



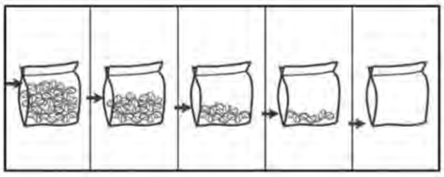
weight loss

ukunciphisa umzimba

b) Medication

store out of reach of children

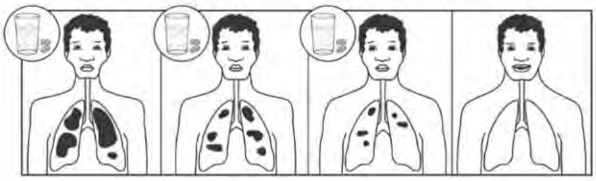
yigcine kude nabantwana



complete the course

gqibezela ikhosi

c) Tuberculosis



lungs clear on treatment

imiphunga iphiliswa lunyango

dead TB bacterium

intsholongwane yeTB efile

alive TB bacterium

intsholongwane ye-TB ephila

d) Miscellaneous

6.3.3. Videos

Participating HCPs' response to videos is detailed in the Data Presentation and Data Analysis chapters. While it was not within the scope of this intervention to create videos, existing videos specific to HIV/AIDS and TB in the South African context were identified when scoping for resources. These could be evaluated or used as a springboard to create new videos for a future definitive RCT.

a) Department of Health and USAID

The DoH has several short videos via the USAID YouTube channel. These are not targeted at HCUs directly, but rather seem to be videos to help build a broader awareness around HIV/AIDS and TB. All of these videos are in English. Videos were included from two TB campaigns: the *USAID TB South Africa Project* and the *Buddy Beat TB* campaign.

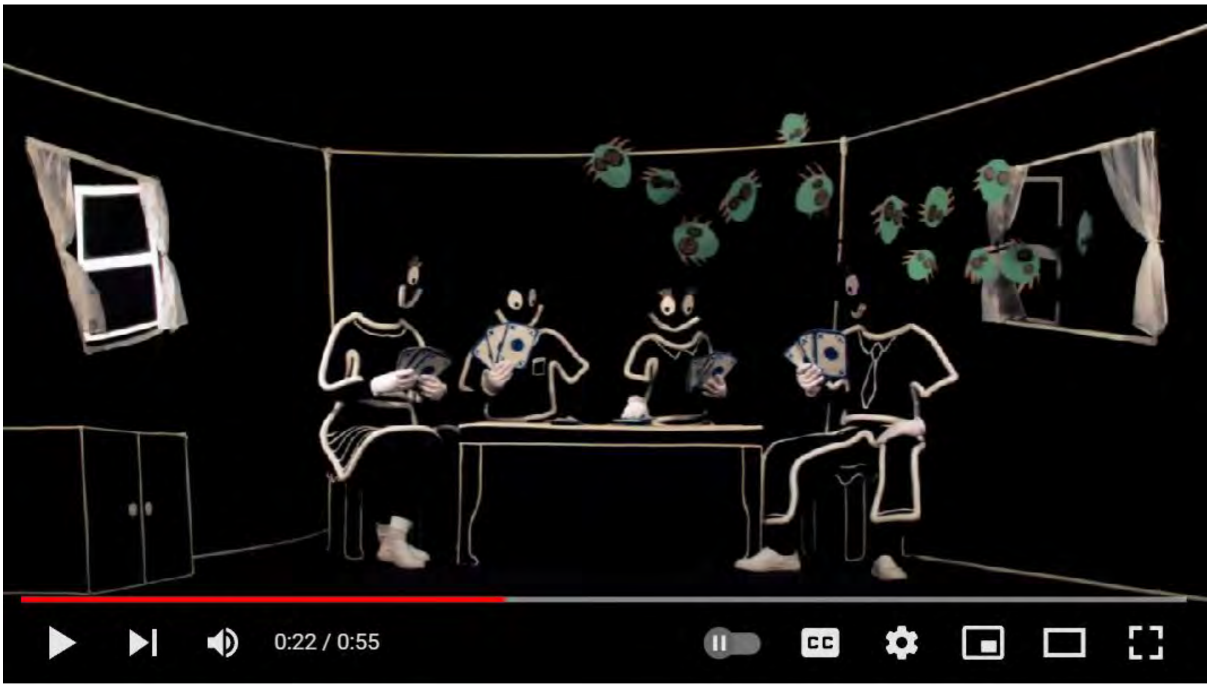


Figure 18: USAID TB South Africa Project: Infection controls (We Beat TB)

This video is from the *USAID TB South Africa Project*, and illustrates the measures one can take to minimise the spread of TB in day-to-day settings.

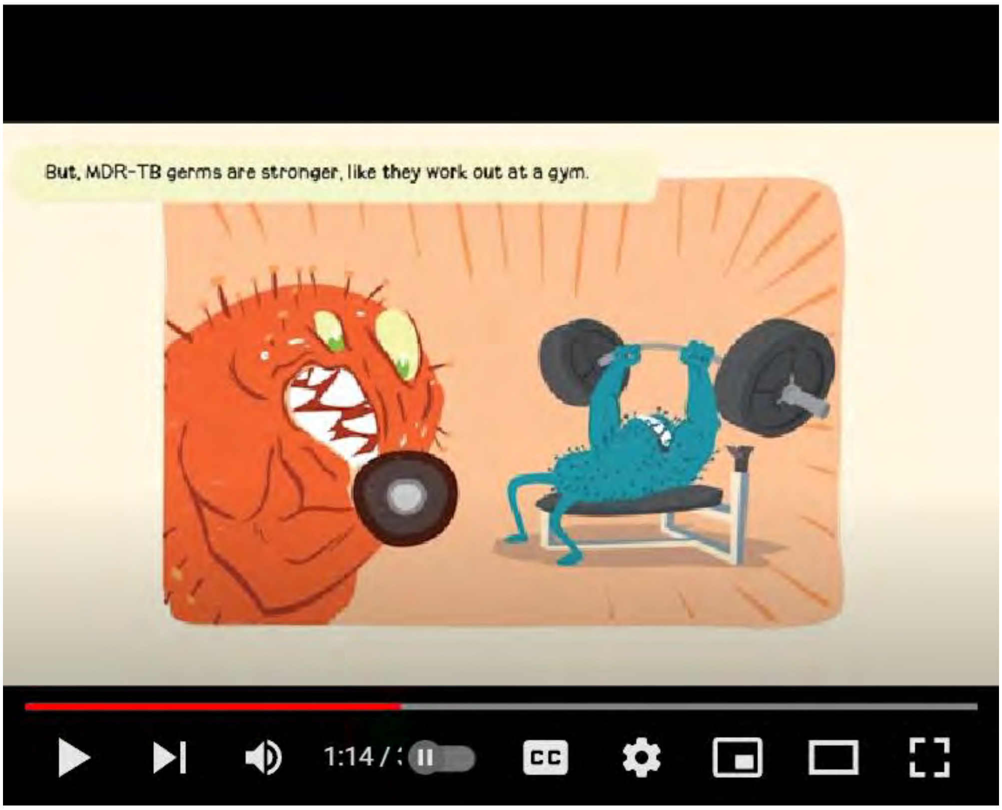

But, MDR-TB germs are stronger, like they work out at a gym.

Figure 19: Buddy Beat TB Part 1 - What is MDR-TB?

The *Buddy Beat TB* campaign is newer than the *USAID TB South Africa Project* and uses animated cartoons to accompany a voice explaining information about TB. This video explains what MDR-TB is and how it can be contracted, and touches on the theme of resistance.

b) Brothers for Life

Brothers for Life is an organisation that aims to build awareness of HIV/AIDS among South African men.

Figure 20: TB HIV balancing act 45

This video stresses the importance of getting tested for TB, whether one is HIV-positive or HIV-negative. The video is short and clear, but is only available in English. While it is on the *Brothers for Life* YouTube channel, it appears to be part of the *USAID TB South Africa Project*.

6.3.4. Other resources

The pamphlet resources were also highlighted in the feedback on the resource preview pack; however, they were not included as part of this intervention due to time constraints. This is discussed in more detail in the Recommendations for Further Research chapter.

6.4. Training manual

The training took the form of a communication manual (Appendix 21) containing explanations and practices exercises, which was given to participants together with the resources. The manual included:

- An introduction to the research
- An explanation of how to use the manual, explaining the visual cues to write, think, or complete and take a photo of a section, and noting the different use of text colours (black and grey).
- Information about the materials, in particular who they were developed by and the creative commons license of the materials developed specifically for this project.
- Study timeline
- Questionnaire #1. This questionnaire consisted of the 6-point scale described in Chapter 7.
- A flashcards section, which included:
    - Participant's reflection on how they already use non-verbal communication.
    - Information about the flashcards and how to use them. This included links and QR codes to three example videos.
    - A practice exercise, which involved looking through the flashcards the participants received, putting together a pack of flashcards, and practice using them.
    - A prompt to decide when and how the participant would like to try using the flashcards.
- A digital flashcards section, which was shorter than the preceding flashcards section as it built on what was already covered. This section included:
    - Participants' reflection on what types of communication they prefer using, including thinking about if they prefer to make a phone call or send a text, and if they prefer to keep their information stored in digital or physical formats.
    - Instructions for how to download the digital flashcards using a QR code, via email, or via WhatsApp.
    - A prompt to decide when and how the participant would like to try using the digital flashcards.
- A translation app section, which focused on the AwezaMed translation app. This section included:

    - Participants’ reflection on how they already use translation and interpreting.
    - Some information about the translation app, how to download it, and how to use it.
    - A role-play practice exercise, which included scenarios in which the app might be useful, and a video (accessible via YouTube link or QR code).
    - A prompt to decide when and how the participant would like to try using the translation app.
    - Questionnaires #2 and 3, which are the same as Questionnaire #1 with the addition of the question “In the past three weeks, how often have you used each of the following?” as outlined in Chapter 7 for the flashcards, digital flashcards and translation app.
- A notes page.

The information sheet and informed consent was not included in this manual and were printed and included in the pack separately to the manual.

6.5. Resource revisions

After the study was completed, some resources were revised and additions were made. All participants received the new or additional resources.

The details of participants’ feedback are discussed in Chapter 7. The details specific to the further development of the resources are included here.

This section answers research question 2: *What communication resources and training are appropriate for the provision of HIV/AIDS and TB healthcare in South Africa?*

6.5.1. Specific feedback from HCPs

Following the implementation of the pilot feasibility trial, feedback from participating HCPs was gathered to inform a final revision of the resources. The adjustments and additions detailed in this section were made before the waitlist-controlled group received their resources. After this, the waitlist-control group received all of the resources and training manual, and the intervention group received the additional resources. No feedback was formally collected on the final revision of the resources; it is highly recommended that this is explored in a full RCT.

a) A hybrid between the flashcards and a glossary

> I think it'd be more helpful to stick to the flashcards format, just maybe you could make the flashcards bigger and then put, like, a respiratory system flashcard. And then have 'Are you short of breath?', 'Are you coughing?', 'Are you like producing sputum?', 'What colour is the sputum?', 'How many days has it been?'. Because these are all questions that we just rattle off and then it gives us really important information. (Chris Kalloway[11], Intern at Lindiwe Sidali Hospital)

In some cases HCPs used the flashcards as visual aids, but in other cases they used the translations on the flashcards as a glossary or as language learning tools. To further support this use, a 'flash-glossary' was created. This was made in a format that was 8cm by 14cm, with headings on each flashcard, and related sets of words or sentences in English and isiXhosa on each card. Unlike the original flashcards, these were printed double-sided to make the packs thinner, since they were not designed to be HCU-facing.

Some words and phrases that were suggested are:

- *Body parts*, for example breasts, liver, lungs, pancreas, penis, skin, stomach, tongue, and vagina.
- *Cardiovascular,* for example palpitations, dizziness and chest pain.
- *Respiratory,* for example 'Is the pain worse when coughing?' and 'Does anyone have TB or Covid at home?'.
- *Neurological/psychological,* for example insomnia, confusion, 'Do you hear voices?', and 'Do you see things that aren't there?'.
- *Abdominal, gynaecological and obstetrics,* for example 'difficulty urinating', 'Do you have any vaginal/ penile discharge?', 'When was your last menstrual period?' and 'Do you use contraception?'.
- *Musculoskeletal,* for example 'Move like this', bone, swollen, and 'Can you feel this?'.
- *Medical history,* for example 'Do you have any medical conditions?', 'Did anyone in your family have cancer/TB/Covid?', 'What medication do you take?' or 'Which regimen are you on?', and 'Have you stopped taking your treatment?'.

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[11] All names of participating HCPs have been changed.

- *Helpful phrases,* for example 'How can I help you today?', 'Are you able to speak English?', 'I am still learning to speak isiXhosa, can you please speak slower,' and 'I am going to get someone to help translate'.
- *Explanations,* for example 'See a doctor if you experience these symptoms', 'These symptoms are normal',
- *Miscellaneous*, for example injection and drip.

Based on these suggestions, the following categories were added to include more of the words and phrases:

- *Descriptors*, for example 'comes and goes', constant, burning,
- *Instructions*, for example 'come back'.

b) *Something for rehab unit/OT/physio etc*

For allied health, particularly OT and physiotherapy, the flash-glossary was also used. The printable format was used because of its ease of use for therapists while they are wearing gloves. The three main topic areas were actions, body parts, and reality orientation. The body parts were included on illustrated flashcards, as described in the above section, and actions and reality orientation were developed as a flash-glossary to include phrases such as "You are in a hospital", "Today is [date] and the time is [time]", "This is my role as [OT/physiotherapist]".

A full set of resources for OT and physiotherapy was not developed as it went beyond the scope of this research; however, the expansion of phrases using the 'flash-glossary' meant that more actions and helpful phrases could be included that could also be used for these consultations. The importance of such resources should not be minimised, however, especially because of (a) the prevalence of language barriers in these professions, and (b) the potentially unexpected style of treatment in these professions, for which reality orientation, explanations, and a good relationship with the HCU are of great importance.

c) *Additions to the app*

The translation app provided a different usefulness to the flashcards: while the flashcards could be used to assist spoken communication and were more fluid (due to speech being made by the HCP and HCU), the app was helpful for direct and more static utterances. In this way, the app could be helpful for providing explanations that would perhaps be too long or complicated for non-isiXhosa-speaking HCPs to attempt themselves in isiXhosa. The app already had several disease-specific explanations included, and the words and phrases that were requested as additions were *CD4 count* and *Viral load*.

6.6. Conclusion

This chapter has explored research question 2 in more detail, examining *What communication resources and training are appropriate for healthcare provision in South Africa*. While this chapter does not explicitly answer the question, it provides initial and improved options for communication resources and training, the appropriacy of which are measured and presented in Chapters 5 and 7.

What has been presented in this chapter may provide examples of appropriate communication resources and training; however, this does not purport to be an exhaustive list, nor are these the 'most' appropriate resources and training. In line with the selection and development of the resources and training being part of a PAR approach, and in line with the evaluation of these resources being a pilot feasibility trial, the groundwork has been laid for further adjustments to be made.

Chapter 7: Pilot feasibility trial

7.1. Introduction

The focus of this study is health communication in the Eastern Cape, South Africa, situated within the context of HIV/AIDS and TB. Two needs analyses were conducted: an online survey open to all HCPs in South Africa to explore their experiences of communication in HIV/AIDS and TB consultations, and another conducted with HCPs at hospitals participating in the pilot feasibility trial, in which resources were suggested and feedback was collected in order to adjust the resources to their needs. The needs analyses were presented in Chapter 5 of this thesis, and Chapter 6 described the development of the resources and training created in response to this. Existing health communication resources were compiled, and some adjustments were made according to the data collected in the needs analyses. A communication manual was created as a guide to accompany the resources. This was put together to create what we have called the *Healthy Talk* intervention. This chapter explores the feasibility of conducting a communication-focused intervention with HCPs working with HIV/AIDS and TB in healthcare sites in the Eastern Cape, and discusses the appropriateness of the suggested resources for different healthcare contexts.

This chapter begins by outlining the *Healthy Talk* intervention that was conducted. The aims of the intervention are defined, and the pilot feasibility trial comparing the *Healthy Talk* intervention with the waitlist control group is described in terms of recruitment, the resources and training that was provided, and the ways in which data was collected. The impact of the COVID-19 pandemic on the setup of the intervention is noted. Six sites participated in this feasibility study: four hospitals and two NGOs. These sites are described in terms of the areas in which they are situated and how resourced they are. The participants from these sites are also described according to the sampling criteria, their professions and their home languages. The feasibility of this study is then investigated in terms of setting up the intervention and conducting the study, in line with the CONSORT extension for pilot feasibility trials. Setting up the intervention is considered with regard to the ethics process, the feasibility of conducting the study primarily online, and the recruitment process. Conducting the study is considered with regard to HCPs’ interest in the study, their existing sensitivity to communication issues, the perceived acceptability of the *Healthy Talk* intervention, and the operational feasibility in terms of participant retention and satisfaction.

The feasibility of the resources is presented and analysed quantitatively and qualitatively. This is done through the presentation and analyses of data from questionnaires conducted before, during and after the intervention, a feedback group conducted on WhatsApp in a focus-group discussion style, individual communication initiated by participants during the intervention, and individual interviews conducted after the intervention.

After exploring and analysing this data, and through reflecting on the context, literature and needs analyses presented in previous chapters of this thesis, recommendations will be made for increased trial feasibility and for the use and implementation of health communication resources. These recommendations will be of relevance to higher education institutions, continuing medical education, and South African policies for health and communication. This chapter is concluded through situating these findings and recommendations within the broader theories of this thesis and the practical implications of the study.

7.2. Methods

7.2.1. Aims of the intervention

The intervention detailed in this chapter focuses on research questions 2, 3, and 4: *What communication resources and training are appropriate for the provision of HIV/AIDS and TB healthcare in South Africa? How feasible is it to implement and measure the suggested resources and training?* and *What are the effects of the suggested communication resources and training in healthcare provision?* These research questions are explored here specifically through the fourth objective outlined in the Introduction and Methodology chapters: *To analyse the effects of the communication intervention in terms of feasibility of implementation and satisfaction*.

7.2.2. Description of the intervention

a) *Feasibility trial set-up*

Sites were identified according to the following criteria:

- Situated in the Eastern Cape
- Provides healthcare services to people living with HIV/AIDS and/or TB
- Could be reached telephonically or via email (due to the Covid-related restrictions on travel implemented in South Africa during the time of setting up the study)
- Could be accessed with ethical clearance obtained from RUESC, Eastern Cape Department of Health, and permission from the site and/or the site’s ethics board.

A total of seven sites met these criteria and agreed to participate in the study. One of these sites was excluded because the HCPs who responded to the invitation to participate worked across two sites, and so the site at which they were primarily based was chosen. The six sites that were included in the study consisted of four public academic hospitals and two NGOs that provided healthcare services.

The participating sites were randomly assigned to a control group and intervention group using the *Random Team Generator* option on randomlists.com. The hospitals were split separately from the NGOs, so that the control and intervention groups each consisted of two hospitals and one NGO.

The sites and their group allocation are described in more detail in the following section.

b) The Healthy Talk resource pack

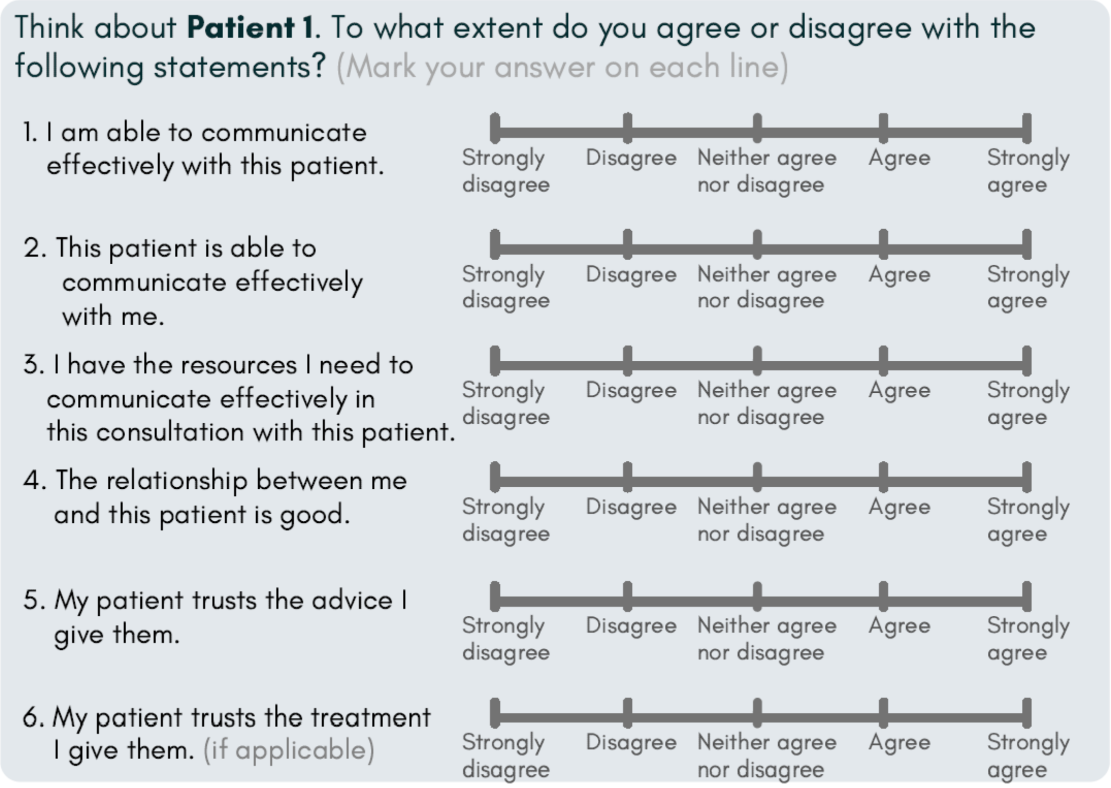
This research began with a review of the literature (Chapter 2), to build a theoretical idea of what communication barriers existed in South African healthcare, as well as what resources and training were available to bridge these barriers. The real-world manifestations of these ideas were then explored through two needs analyses conducted with healthcare professionals (Chapter 5). This elucidated the communication goals (see Hulsman, 2009) of participating HCPs. Communication resources were identified and developed (Chapter 6), and put together into what we called the *Healthy Talk resource pack*. This pack consisted of:

- A communication manual with explanations of the resources and suggestions for how to use them, a timeline, T1-T3 printed questionnaires, and including links to example videos, to download digital flashcards, and to download the translation app;
- A set of 'flashcards': laminated business-card-sized cards, each illustrated with a black-and-white pictogram with a short description written in English and isiXhosa;
- Clip-rings for HCPs to use to make flashcard packs themselves;
- A USB stick with video examples of how to use the resources.

Picture 2: Healthy Talk resource pack

Picture 3: Flashcards (included in the envelopes in the resource pack)

Three questionnaires were included in the *Healthy Talk* resource pack. For each questionnaire, participating HCPs were prompted to think back to their last four consultations by writing down the initials of the last four HCUs to whom they provided healthcare services. For Questionnaire #1, they were asked to complete the following scale for each HCU:



Think about **Patient 1**. To what extent do you agree or disagree with the following statements? (Mark your answer on each line)

1. I am able to communicate effectively with this patient.
Strongly disagree — Disagree — Neither agree nor disagree — Agree — Strongly agree

2. This patient is able to communicate effectively with me.
Strongly disagree — Disagree — Neither agree nor disagree — Agree — Strongly agree

3. I have the resources I need to communicate effectively in this consultation with this patient.
Strongly disagree — Disagree — Neither agree nor disagree — Agree — Strongly agree

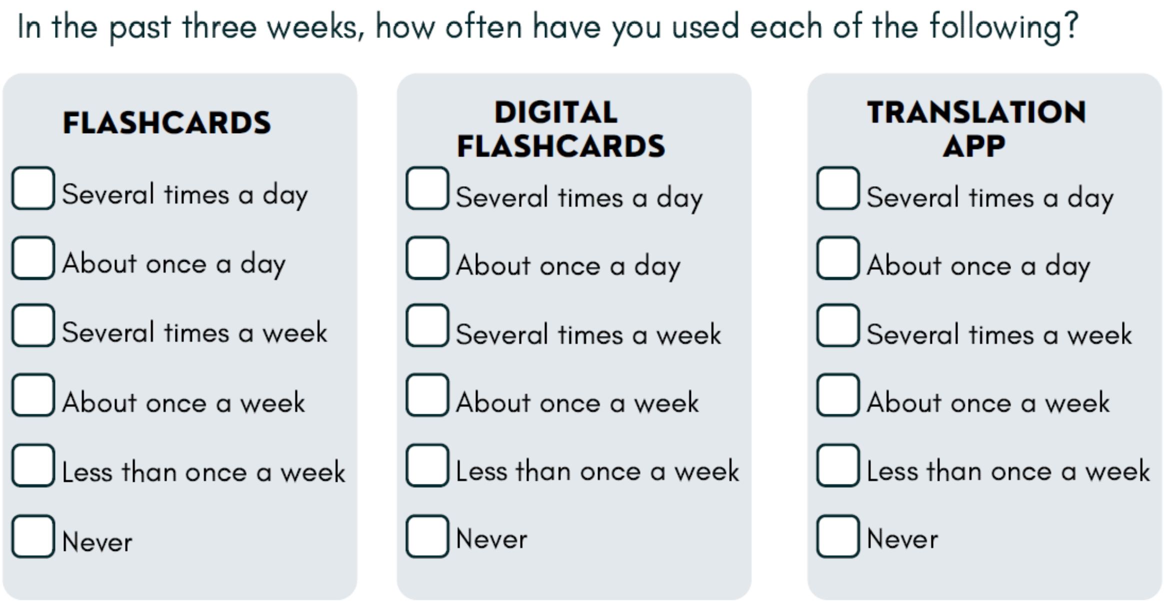
4. The relationship between me and this patient is good.
Strongly disagree — Disagree — Neither agree nor disagree — Agree — Strongly agree

5. My patient trusts the advice I give them.
Strongly disagree — Disagree — Neither agree nor disagree — Agree — Strongly agree

6. My patient trusts the treatment I give them. (if applicable)
Strongly disagree — Disagree — Neither agree nor disagree — Agree — Strongly agree

Picture 4: Questionnaire #1 scale

Questionnaire #1 was completed at the time each HCP received their resource pack, before the intervention began. They were then encouraged to self-study the communication manual and use the provided resources as much (or as little) as they would like over the next two months. Hulsman (2009: 305) notes that *self-efficacy* is one of the main determinants of intention to perform a behaviour; one may therefore expect that someone who self-studies a manual would also be more likely to change their behaviour. After four weeks, all HCPs were asked to complete Questionnaire #2. This questionnaire consisted of the same scale for the last four HCUs they consulted, and also asked the following about the HCP’s use of the provided resources:

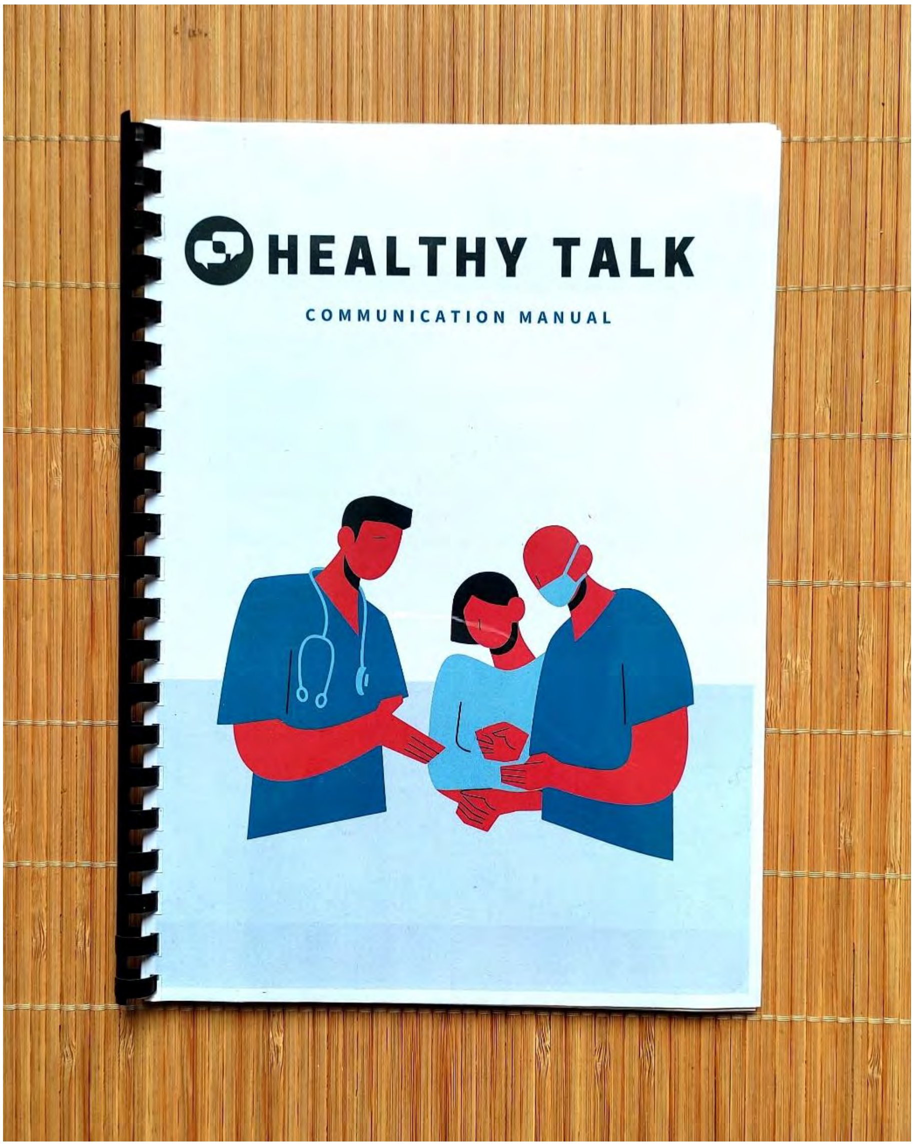


In the past three weeks, how often have you used each of the following?

FLASHCARDS	DIGITAL FLASHCARDS	TRANSLATION APP
☐ Several times a day	☐ Several times a day	☐ Several times a day
☐ About once a day	☐ About once a day	☐ About once a day
☐ Several times a week	☐ Several times a week	☐ Several times a week
☐ About once a week	☐ About once a week	☐ About once a week
☐ Less than once a week	☐ Less than once a week	☐ Less than once a week
☐ Never	☐ Never	☐ Never

Picture 5: Questionnaire #2 and #3 resource use

Each participating HCP from the intervention site received their own *Healthy Talk* resource pack. HCPs from the control sites did not receive a resource pack, but instead received the questionnaires printed as a booklet. This booklet contained a timeline and three questionnaires, which were completed at the same timepoints as those conducted with the intervention group.



Picture 6: Questionnaire booklet for control group

In most cases HCPs were asked to complete Questionnaire #1 when they received the resource pack or questionnaire booklet, after which I or my research assistant took a photo of the questionnaires. Thereafter all HCPs were asked to send their questionnaires directly to me by taking a photo of each page and sending it to me via WhatsApp, or by scanning it and sending it to me via email.

Some HCPs misplaced their books or were in another town when it was time to complete the questionnaire. As an alternative to the hardcopy questionnaires, participating HCPs were given the option to complete the same questionnaire online via the Survey Monkey platform.

After a suggestion from the control group (discussed in more detail later in this chapter), all HCPs were requested to note the language of each HCU (if known) next to each scale they completed.

c) WhatsApp group chat

In the information given about participating in the research, it was made clear to HCPs that, if they were assigned to the intervention group, participation would include completing three questionnaires, participating in midline feedback via a WhatsApp group chat or a Zoom focus group discussion, and giving more detailed feedback in an optional final interview. If they were assigned to the control group their participation would include completing three questionnaires only.

All of the participants in the intervention group selected to participate in the midline feedback via a WhatsApp group chat, or they did not have a preference between a WhatsApp group chat or Zoom focus group discussion. No-one selected a Zoom discussion as their only preference. Therefore, it was decided to conduct the feedback session via a WhatsApp group chat.

Fifteen participating HCPs were added to the WhatsApp group, together with myself (as the group admin) and the research assistant. Of these participants, seven gave feedback in the group, and eight gave no feedback. Of those who gave feedback in the group, one also gave additional feedback to me personally via WhatsApp when they sent Questionnaire #2. Of those who did not give feedback in the group, one also gave additional feedback to me personally via WhatsApp when they sent Questionnaire #2.

7.2.3. Description of sites

All of the sites were located in the Eastern Cape, South Africa. The names of each site have been changed to preserve the anonymity of participants.

a) Control Group

i. Nomusa Shezi Hospital

Nomusa Shezi Hospital is a tertiary teaching hospital. It is a large provincial, government-funded hospital in a medium-sized coastal city in the Eastern Cape. It is part of the same hospital complex as Lindiwe Sidali Hospital.

In my experience of visiting the hospital, it gave the impression of a Foucauldian institution: while there is a big main entrance to the hospital, all visitors have to enter through the small pedestrian side gate, creating a feeling of disempowerment at one's first encounter of the hospital. In contrast to Lindiwe Sidali Hospital, where we were always greeted by staff (even though they did not know who we were), here we were ignored to the point that we had to squeeze past HCPs in order to enter the office of the head of radiology with whom we had an appointment. She explained that while the research would not be relevant to her department, it would be relevant to the HCPs at the ARV clinic, and she gave us directions for how to reach the clinic and who to speak to. On the way to the ARV clinic we walked a roundabout route because there were several signs on doors saying that the door was not for HCUs to use, and that people who wanted to access the ARV clinic should go around the side of the building. In this way, the spaces in the hospital may give the HCU a feeling of being unwelcome, or an inconvenience – rather than a space to be welcomed and supported.

ii. Ncumisa Jilata Hospital

Ncumisa Jilata Hospital is also a tertiary teaching hospital. It is a large provincial, government-funded hospital in a large coastal city in the Eastern Cape. It is part of the same hospital complex as two other hospitals; however, one of these hospitals was not included in the study as the team of HCPs who would participate in this study worked across both of these hospitals and were primarily based at Ncumisa Jilata Hospital.

iii. Xuma Foundation

Xuma Foundation is an NGO that supports a remote rural hospital through supplying medical equipment and employing interpreters to work with healthcare professionals at the hospital.

Despite having reached the participant at Xuma Foundation during the needs analysis study (detailed in Chapter 5), it was not possible to reach this participant via phone or email at the time of the pilot feasibility trial, and it was also not possible to travel to this site in person. A resource pack was couriered to this participant, but no responses were received and thus this site was not further included in this study.

b) *Intervention Group*

i. Lindiwe Sidali Hospital

Lindiwe Sidali Hospital is a tertiary teaching hospital. It is also a large, provincial, government-funded hospital. It is situated in a large township close to a medium-sized coastal town in the Eastern Cape. It is part of the same hospital complex as Nomusa Shezi Hospital. This hospital is made up of two main buildings: one recently renovated, and one run-down and dilapidated. The recently renovated building has the feel of a teaching hospital from a medical TV drama: it is very large, bright, and spacious, with expansive windows, and scattered with welcome desks that were never filled. One HCP explained that the old building, on the other hand, “looks like it’s run-down from not being used, but it’s actually always been like that.” When giving us directions to a meeting room in the old building, another HCP described that we turn right, go down a long corridor, and “when it smells mouldy, you know you’re in the right place.”

ii. Mary Malahlela Hospital

Mary Malahlela Hospital is a tertiary teaching hospital. It is a large provincial, government-funded hospital in a large coastal city in the Eastern Cape. It is part of the same hospital complex as Ncumisa Jilata Hospital.

iii. Njongwe Support Centre

Njongwe Support Centre is an NGO that provides support – such as food, clothing, schooling and healthcare – to people living in the township where Mary Malahlela Hospital is located.

7.2.4. Description of participants

a) *Sampling criteria*

Purposive and snowball sampling was used: The sample size was based on the main objective of the pilot feasibility trial (which is discussed in more detail below, under *Trial feasibility*). The sampling criteria was any HCP who provided services to people living with HIV/AIDS and/or TB. Participants were not chosen based on language or specific healthcare profession. The professions of the HCPs who participated in (at least) T1 were as follows: one dietician; one doctor and one social worker in two respective ARV clinics; two doctors and five interns in a Family Medicine department; four doctors in an Infectious Diseases Outpatient Department (OPD); one doctor in an Internal Medicine department; one nurse at an NGO clinic; four Occupational Therapists (OT); and one Speech and Language therapist.

Participants were not asked for their home language, but their isiXhosa proficiency was noted as this is the language used by most HCUs. The Social Worker in the ARV Clinic was the only participant who spoke isiXhosa as L1; the Doctor in the ARV Clinic spoke Spanish as her L1, the Doctor in Internal Medicine said her L1 was “too complicated to explain” but that she could speak “medical isiXhosa and that’s all”, and all other participants spoke English or Afrikaans as their L1, with several commenting that they would attempt to speak isiXhosa or could speak broken or limited isiXhosa.

b) Participant flow

i. Sites

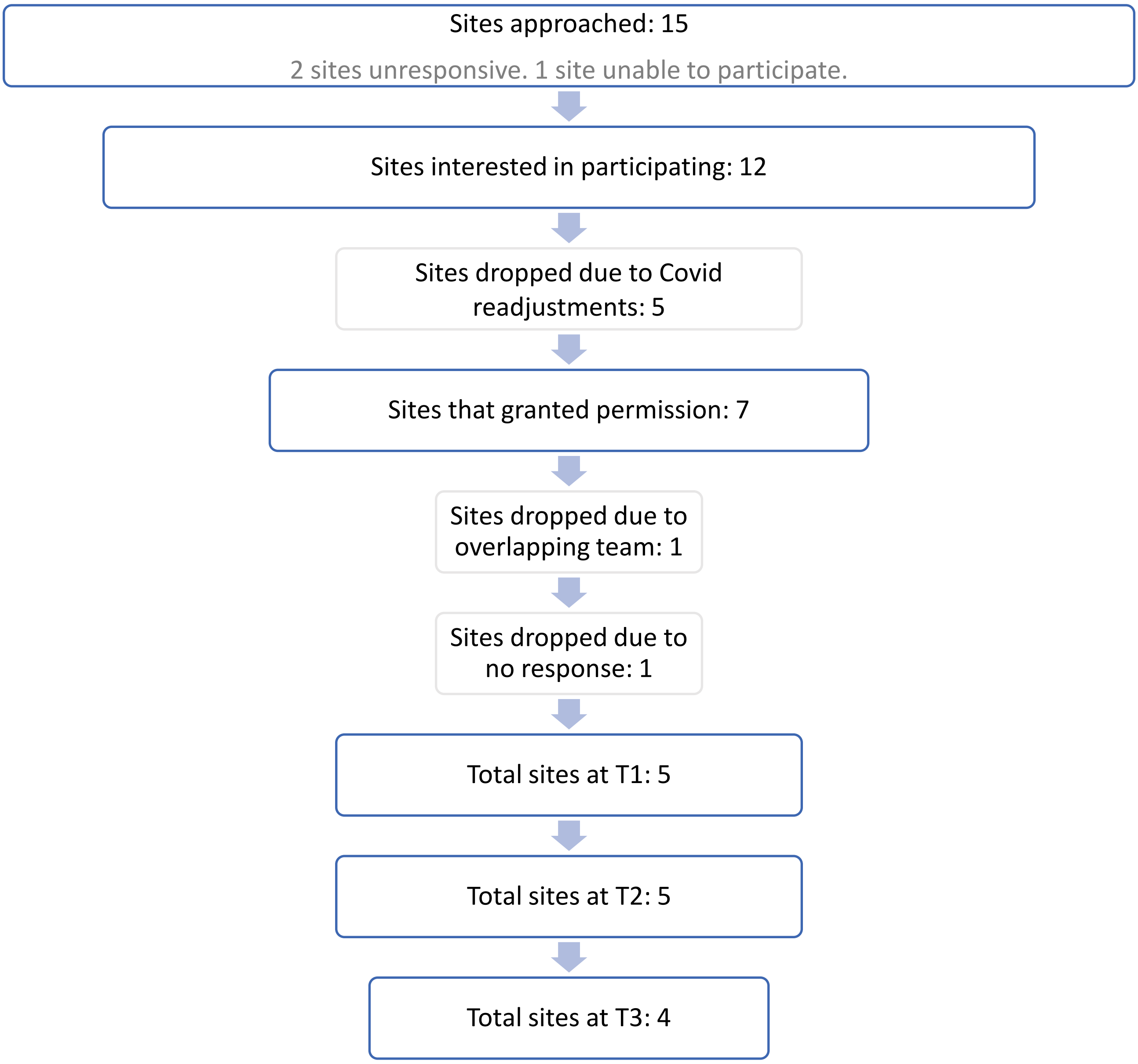


Figure 21: Participant flow diagram for sites

ii. Healthcare professionals

It should be noted that number of dropouts is indicative, but not definitive, of the appropriacy of the intervention and its acceptability. This is illustrated in Figure 25 in more detail.

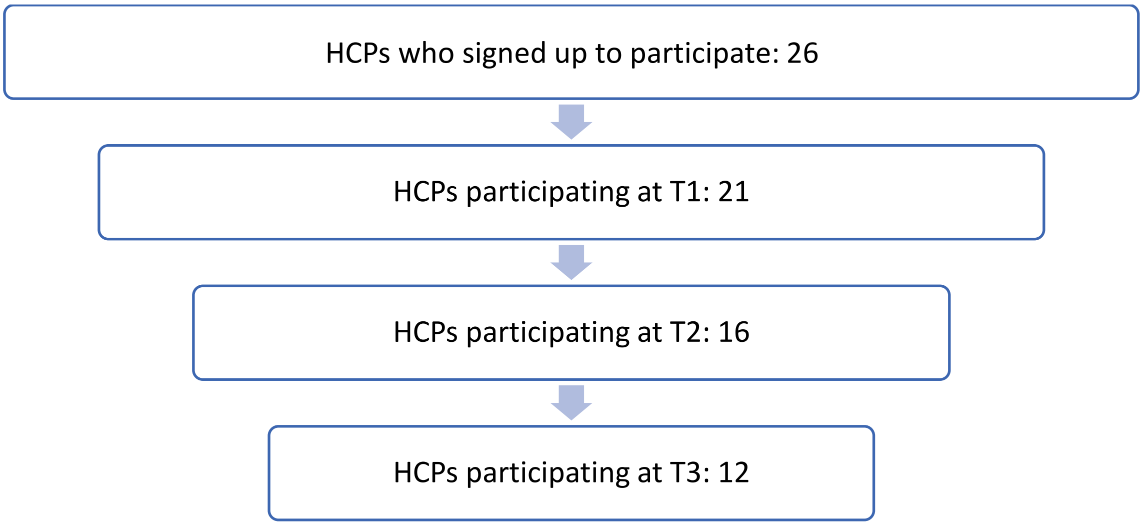


Figure 22: Participant flow diagram for HCPs

As explained by Sekhon et al.:

> Whilst the use of measures of observed behaviour does give an indication of how many participants initially agree to participate in a trial versus how many actually complete the intervention, often reasons for discontinuation or withdrawal are not reported. There are several reasons why patients withdraw their participation that may or may not be associated with acceptability of the intervention.
> (Sekhon et al., 2017: 9).

This was certainly the case in this study, as most often when HCPs dropped out they "ghosted" me, that is, they stopped responding to my attempts to reach them via WhatsApp or email. In some cases, participants explained that they would not be able to continue with the study: at the time of signing up, one HCP at Lindiwe Sidali Hospital expressed his uncertainty of having time to participate, and later dropped out before completing any questionnaires due to being on sick leave with Covid; another HCP at Lindiwe Sidali Hospital signed up enthusiastically and offered to assist further if needed, but then dropped out after T2 due to having taken on more responsibilities since the start of the study.

7.2.5. COVID-19

With the COVID-19 pandemic, many of the ways we do things had to change. At the time of writing, it appears that the world is – broadly speaking – returning to normal or to a 'new normal'. There are some pre-pandemic ways of doing things that we have returned to without questioning, and other ways of doing things that we learnt or adapted during the pandemic that will be here to stay. Since this research was adjusted for the pandemic, it begs the question *is this a viable way of conducting research*? In this chapter we consider this question both within the context of a global health crisis, and in the more general context of research best practice.

In the initial planning stages of this research, ‘hard-to-reach’ sites were prioritised, especially those in remote areas and with few resources. However, the Covid-related restrictions came into force during the recruitment stages of this research. In the months preceding the lockdown, several remote and/or under-resourced government-funded hospitals had been contacted, five of which showed interest in participating in this study but were not included in the study. One of these, a remote hospital, did not participate because, as the Clinical Manager informed me, the hospital staff were “stretched” due to the Eastern Cape DoH not making any replacement appointments in the previous six months, and the staff were already participating in a few other studies. The remaining four hospitals consisted of two general hospitals and two hospitals specialised in TB care. These hospitals had all been contacted over the phone and confirmed that they would be interested in participating, but that they could only participate once permission had been granted from the District Office for each district (in addition to the ethical clearance certificate from the provincial DoH ethical clearance). In the experience of setting up this study it was found that it was generally more feasible to contact and request ethical clearance from sites directly than it was to apply for permission to access the sites from the District Departments of Health, which became even more apparent when South Africa went into its first lockdown. As it was not possible to visit the District Office in person, it became clear it was not possible to apply for permission from this office, and alternative options were considered. It was then decided to only include hospitals that had their own ethics boards, for which permission was obtained through the submission and acceptance of the RUESC ethical clearance, the DoH ethical clearance, the research proposal and an application form.

7.3. Trial feasibility

Pilot feasibility studies are often conducted in preparation for randomised controlled trials. In this section the feasibility of the intervention is looked at in terms of how successfully it could be implemented as a future randomised controlled trial. This is reported on in line with the CONSORT extension for Pilot and Feasibility Trials (Eldridge et al., 2016a) (see Appendix 24). Once this has been discussed, the following section evaluates the feasibility of the resources as ancillary analysis.

Thabane et al. (2010: 7) point out that pilot studies should explicitly state what determines the study's feasibility, and the NIHR (cited in Eldridge et al., 2016b: 14) requires clear progression criteria to indicate whether the pilot feasibility trial should progress to a full-scale study. In this case, feasibility was determined in line with recommendations made by Shanyinde et al. (2011). As per Shanyinde et al. (2011: 9) the following were examined: recruitment (bearing in mind that "referrals from clinicians are likely to depend on the RCT context"; randomisation procedures; blinding procedures; retention (noting that "[r]etention may differ between experimental and control groups, and may depend on treatment preferences"; logistics of multi-centre trial; consent; and how well all the components of the protocol work together. Some notes are made about the duration of the intervention. Related to trial feasibility, but not specifically recommended to be included in a pilot feasibility trial (Shanyinde et al., 2011: 9) and therefore not considered particularly with regard to feasibility but rather with regard to the resources themselves, are compliance/adherence to the intervention and acceptability of the intervention. These are included in the ancillary analysis.

7.3.1. Ethics

This research planned to begin with participatory action research to identify the problem and proposed solution, and then do the feasibility trial. At the time of starting this research, all of this needed to be done in one ethics application to the university ethical standards committee. However, concurrent to the undertaking of this research, the Rhodes University Community Engagement Department worked with the RUESC to include ethics procedures for this style of research, so that one application could be made to begin the PAR section, and then once the problem was more clearly defined and the proposed intervention outlined, another ethics application could be made. This will undoubtedly have a positive effect on conducting this type of research in the future.

7.3.2. Online vs in-person

While some elements of this research could easily be conducted online (particularly sending questionnaires via WhatsApp), the in-person element – when and where possible – continues to play an important role. It was only when visiting the hospitals in person that I could fully realise how the hospital structures work, and what the work culture or environment of the hospital was, especially in terms of knowing who to speak to, or who to approach in order to do something. Understanding of the context in this way is important in terms of building epistemic trust and avoiding helicopter research.

7.3.3. Acceptability as illustrated by recruitment and interest

It is necessary to consider the acceptability of the intervention to better understand the potential effectiveness of the intervention, which should be considered both in terms of HCPs' and HCUs' perceptions (Sekhon et al., 2017: 1). In this analysis we consider acceptability from the HCPs' perspective, and, where possible, the assumed acceptability from the HCUs' perspective as reported by HCPs. As the latter is not necessarily reliable it is included anecdotally rather than definitively. If HCPs consider the intervention or parts thereof to have low acceptability, it is possible that they would not implement it as intended and therefore the impact, uptake or effectiveness of the intervention could be affected (Sekhon et al., 2017: 2). HCPs' considerations of acceptability could be seen in, for example, their questions about the study protocol, and about the resources themselves.

a) Snowballing from the top down

> *"This will just sit on my desk, but let me take you to speak to the people who will actually use it"*
> (Clinical Manager, Head of Family Medicine, and Rehab Unit Manager at Lindiwe Sidali Hospital)

While purposive and convenience sampling was used in selecting the sites, snowball sampling was used to recruit HCPs at the sites, with management or interested HCPs introducing us to or putting us in touch with others who may have been interested. Across the sites it was found that having the support of management played an influential role in uptake among potential HCP participants. When explaining the study, on three separate occasions an HCP in a management role at Lindiwe Sidali Hospital interjected with "This will just sit on my desk, but let me take you to speak to the people who will actually use it" after which they would accompany us to speak with other HCPs. Even though these HCPs did not participate, their understanding of and interest in the project enabled them to explain it to their colleagues and encourage their colleagues to participate. At sites where we did not have active support from management figures, the feasibility of the study was dependent on HCPs choosing to participate because they were already concerned about communication barriers.

The value of a top-down approach at certain sites is also illustrated by an invitation from the Clinical Manager at Lindiwe Sidali Hospital to present the research at the HoDs' meeting. He explained that in order to reach the maximum number of HCPs, it would be helpful for us to speak with the HoDs to gain their support first. Unfortunately this presentation was cancelled at short notice due to the HoDs' meeting being rescheduled because of "prioritising agendas", so it is not possible to report further on the impact that this would have had on uptake and feasibility. However, relevant HoDs had already been identified and spoken to through the snowball sampling approach we had been conducting concurrently.

Further reflecting the importance of following established hierarchies and norms, adhering to the permission process was focused on more by management staff at the sites where a top-down approach was apparent, compared to the sites where snowball sampling was used to identify individual HCPs. At the three sites with a stronger top-down approach, specifically Ncumisa Jilata, Nomusa Shezi, and Lindiwe Sidali Hospitals, particularly the latter two, management staff would ask specifically to see the hospital-specific permission letters. In the other sites, where HCPs were approached individually to participate, they did not ask to see permission letters.

Lindiwe Sidali Hospital also had a formalised approach to meetings: each meeting started with everyone introducing themselves, after which the person who called the meeting would introduce me and my research assistant. We would then introduce ourselves and talk about the study, after which everyone would be invited to ask questions. At the end of each meeting we would ask who was interested in participating in the research, and take down their details once the meeting had been concluded. This gave greater opportunities to gain the support of management figures, and played a valuable role in attaining informed consent, as potential participants could hear about the study in sufficient detail, discuss it with me and the research assistant and their colleagues, and then make a decision about whether or not to participate and/or to recommend the study to their teams.

The Head of Family Medicine introduced us to the doctor at the ARV unit, and during this introduction two other HCPs were present. Before we explained the research they explained to us that the other two HCPs would not be participating because they would be leaving the unit in two weeks, but they stayed to find out about the research, and showed interest in the resources and the study. In this case it was helpful to have other HCPs present, even though they would not participate, because they helped to shed a positive light on the research through their interest in the project.

After presenting the research to all HCP staff in the Family Medicine Department at Lindiwe Sidali Hospital, HCPs were invited to speak to me individually if they were interested in participating (rather than asking HCPs individually or publicly if they would like to participate). This was an easy to implement strategy to gain informed consent with minimal concern for external pressure to participate, especially as there was a large number of HCPs.

Having the opportunity to speak to HCPs individually after presenting the study and the resources was also beneficial in finding out more about their thoughts and experiences. After presenting to the Family Medicine department at Lindiwe Sidali Hospital, two interns spoke to me afterwards to tell me that they had not seen anything like the communication resources before. They explained that they usually do their best with the broken isiXhosa they can speak, and that sometimes they would ask a nurse to interpret but noted that there were not many nurses so there was not always someone available, and they were concerned that looking for a nurse to assist with interpreting increased HCU waiting times. They were particularly happy that the resources included translations in isiXhosa. The resources were displayed on the table next to me, and here this had a positive effect in increasing interest in the resources as HCPs would pick up and look at the resources while waiting to sign the attendance register, waiting to sign up to participate in the study, or just waiting for their colleagues. Having professionally laid-out and visually appealing resources added to this positive effect, for example the Doctor of Infectious Diseases at Ncumisa Jilata noted that she thought the questionnaire pack was visually appealing. The Doctor of Internal Medicine at Mary Malahlela was also impressed with the resource pack, and was surprised that each participant would receive their own pack because of how much was included in it (noting that there was even a flash drive included).

HCPs were generally interested in the resources but often hesitant about participating in the study. For example, the Heads of OT and Speech and Language Therapy showed enthusiasm about the resources in our initial meeting, and took photos of the flashcards so that they could show them to their teams. But when I spoke with the Head of OT the following day, she told me she was having a hard time recruiting members of her team to participate. She noted the paradox of this difficulty, saying that all of them at some point had struggled with recruiting participants for their own research, but were also reluctant to participate in the research of others. She believed that the reason people were reluctant to participate was because they did not know how easy it was to participate, and so she had explained to her team that participation in this study only involved three short questionnaires, and sending a voice note after one month, which in her view was very easily doable. Also noting the difficulty experienced in recruiting HCPs to participate in research, the Doctor in Infectious Diseases at Ncumisa Jilata felt that it was difficult to recruit people to participate in research "because they are lazy", and she described how it always felt like she was twisting someone's arm to do something.

Resistance to participating in research due to a perceived higher workload was also evident when we met with a doctor at the ARV clinic at Lindiwe Sidali Hospital. We were introduced to her by the head of Family Medicine, who was present when we explained the study and asked if she would like to participate. After explaining the study she seemed very apprehensive and alluded to her opinion that participating would be complicated and a lot of work.

Noting her apprehension, I emphasised that the study was focusing on HCPs who had a particular interest in participating, and that we do not expect everyone to want and/or be able to participate. She responded by joking that she had to say yes because her boss was there.

Some of her concerns and misunderstandings included:

- The workload of participating was too much on top of her existing workload.
- Whether HCUs also needed to sign the consent forms. It was then explained by myself and the other HCPs present that this was not necessary, as the study did not ask any personally identifying information about any HCU, and that the questionnaire only asked about the HCP's experience and interpretation of communication in the consultation.
- How often and when she needed to complete the questionnaires. She had thought that she needed to report on many more HCUs, or on the same HCUs each time – both of which would have been considerably more difficult to do and explain why she was so apprehensive of the seemingly large workload of participating.

- Remembering to complete the questionnaires. We agreed that the research assistant could come to the hospital at the measurement moments and remind her to do the questionnaires.

After everything had been clarified by myself, and with extra clarification from the Head of Family Medicine and the other HCPs present, she said that she understood everything and was happy to participate. Illustrating the impact of language and communication barriers, she blamed her 'Spanglish' (Spanish-English) for misunderstanding the research while the other HCPs present had understood it. As the study progressed it was not necessary for the research assistant to return to the hospital to remind her to do the questionnaires, as she sent all of her questionnaires to me via WhatsApp on time and without any extra reminders.

Even though this participant seemed much more at ease with participating after the study had been clarified, I also followed up with her privately via WhatsApp to check whether or not she would like to participate, and she confirmed that indeed she would. In order to balance the possibility of coerced consent with the importance of top-down support in this trial, it was recommended that supervisors be involved in the introduction of the researcher to potential HCP participants, but that the researcher can discuss consent with the participants individually, or that participants can sign up individually (as with the whole of Family Medicine department). In cases where this was not possible, it was recommended that consent be confirmed again at a later time when the supervisor was not present.

When I met with the participants at the control sites of Nomusa Shezi and Ncumisa Jilata Hospitals, they were enthusiastic about the resources, and very happy to take part in the study. They all told me that sending the questionnaires to me would be easy for them to do, and they generally remained responsive on WhatsApp.

Furthering the snowball sampling, one of the physiotherapists at Mary Malahlela suggested again that I speak with the Doctor of Internal Medicine, the former Head of Internal Medicine, about the study, as she noted that she was very interested in "these types of things". The Doctor of Internal Medicine had already participated in the second needs analysis study, but I had been unable to reach her to arrange to meet with her for the pilot feasibility trial so the physiotherapist accompanied me to find her. She also suggested that I speak to the speech therapist and OT and showed me where their rooms were. I briefly introduced myself and the study to the OT, who listened politely but was rushed and not particularly interested in knowing more about the study. She suggested I leave my details for the speech therapist, who was not there that day and did not contact me. These interactions further reflect the greater potential for uptake when the study and the researcher are introduced by figures of authority or people who hold respect, rather than approaching people individually.

Although the Doctor of Internal Medicine at Mary Malahlela Hospital had been relatively difficult to find (as she was not responsive by phone, and sometimes not at the hospital when I visited), it was clear when I met with her why other HCPs had so strongly suggested I speak with her. She invited me to speak with her in her office, where she discussed the study and the resources together in detail. She recognised the pictograms from reading Dowse's articles, but had not seen them printed for use in real-life contexts. She looked through every flashcard and the translation of each card, and gave detailed feedback and suggestions (detailed in the ancillary analysis). She particularly liked the TB cards as she said they really stood out to her as helpful. To continue with snowball sampling, she took one pack for herself, and two more to try recruit two other interns, telling me that she hoped that others would see the resources and "be jealous", and that this would incentivise them to participate too.

The Dietician at Mary Malahlela informed me that the Doctor of Internal Medicine put me in touch with him because he was the only doctor who would see all of the adults in all of the departments. He was eager to participate in the study because he already had a great interest in bridging language barriers: he had requested isiXhosa lessons at the hospital every year in his staff feedback for the past nine years. He believed the resources would be beneficial to him, particularly as he explained that sometimes it would take 20 minutes for him to find someone to interpret for him, and that even with someone interpreting he would be concerned about whether everything was coming across in the translation. This reflects the findings of Anthonissen and Sobane (2013: 272) and Crawford (1999: 35) about HCPs' dissatisfaction with informal interpreting, and underscores the need for resources and training which better equip HCPs to communicate with HCUs in cases where they do not have access to an interpreter.

b) *Interest in the study*

The literature reflects a great interest in health communication in South Africa from the late 1990s to the mid/late 2000s with Crawford and Levin for example. Under apartheid there were disproportionately more white doctors, and when apartheid ended it did not mean that suddenly the demographics of South Africa's healthcare professionals immediately represented the population. Although most undergraduate medical students at South African medical schools are Black African (38.7% in 2016), followed by White (33%), Coloured (13.4%), and Indian/Asian (13.6%), the demographic distribution still does not reflect the broader demographics of South Africa (van der Merwe et al., 2016: 76).

However, with the passing of time after apartheid and the implementation of more inclusive university application processes, the healthcare sector in South Africa has become more integrated. Bearing in mind the five or six years of study involved in doing a medical degree, the demographics of South Africa's healthcare professionals have gradually become more representative of the population. This means that language barriers do not necessarily exist to the same extent as they did during apartheid or indeed when health communication drew attention in academic literature 10–15 years ago. Besides race, other factors also impact language barriers, for example South Africa's diverse linguistic landscape, and considering the placement of HCPs for their internships and community service years in different provinces.

It was observed at the sites visited for this study that the demographics of HCPs working in the rehabilitation units (which include occupational therapy, dietetics, speech and language therapy and physiotherapy) were disproportionately White. This reflects Ned et al. (2020), that shows how, despite higher growth in Black African and Coloured population groups, the Occupational Therapy (OT) workforce remains disproportionately White.

Following the snowball sampling implemented in recruitment, several HCPs at Lindiwe Sidali Hospital suggested that we recruit HCPs from the Family Medicine department because (a) this department works most commonly with counselling people living with HIV/AIDS and/or TB, and (b) at the time of the study there was a new cohort of interns who did not speak isiXhosa. Indeed it was with this group at the Family Medicine department where the most interest in and support for this research was found, with five interns signing up to participate, and with the interns later accounting for almost a quarter (24%) of participating HCPs, and 100% of interview participants.

At Lindiwe Sidali Hospital several HCPs asked if I had been in contact with the neighbouring TB hospital, or suggested that I do so. They noted that the resources would be particularly useful there, and one HCP who previously worked at the TB hospital before working at Lindiwe Sidali Hospital confirmed the need for communication resources at this site, as during her time working at the TB hospital she developed her own communication resources in the form of posters for DR-TB. This HCP also asked if there was room for more resources to be developed, because of her interest in developing communication resources. In addition to the posters she developed while at the TB hospital she also has a social media page about health communication. However, attempts to reach her via WhatsApp and email to discuss this in more detail were unsuccessful, likely pointing to the common experience of being interested in health communication but not having or prioritising time to participate in research about it.

While the TB hospital was not included in this study, I had been in touch with them during initial recruitment/scoping phase: the hospital staff I had spoken to were interested, but permission was required from the District Department of Health in order to conduct research at this hospital. As discussed earlier, all sites that required District approval could not be included in this study. But this feedback indicates that this intervention would certainly be well-suited to TB hospitals in South Africa (see Chapter 1 for more details on this specific type of hospital).

It is also worth noting ideas around incentivising or rewarding people for participating in research. Appropriate incentives or rewards for participating in research are more contested in poorer contexts, particularly in the Global South. While in well-resourced countries and communities a ‘small’ financial reward is often offered to participants, this can often be seen as questionable at best and coercive at worst in low-income contexts. Even though this study focused on HCPs (not regarded as particularly economically at-risk) and not HCUs (who, especially at the selected sites, could be regarded as economically at-risk), it was decided that financial incentives were not appropriate. In order to improve recruitment, and to show appreciation for participation, resources can be an appropriate reward or incentive in similar trials. If resources are included in the study it is recommended to ensure they are made as appealing and professional as possible, and if they are not included as part of the study relevant resources could be offered as incentive or reward for participating.

c) *Specialisation-specific*

Before deciding on whether or not to participate in the study, some HCPs – specifically the Clinical Manager and the Dietetics Manager at Lindiwe Sidali Hospital – asked about the possibility of changing or adding to the cards. It was explained that the resources that we presented were already the finalised resources for this intervention, but that the cards could be adapted or added to after the intervention. The Dietetics Manager at Lindiwe Sidali then explained that she would not participate in the study because the cards she would need were very specific. The Dietician at Mary Malahlela Hospital, on the other hand, decided to participate, for the reasons described in Chapter 7.

Similarly, the Head of the Radiology Department at Nomusa Shezi Hospital was interested in the study, but she explained that the study would not benefit from the involvement of the Radiology Department, as they did not spend a lot of time with HCUs, and because they also saw relatively few HIV/AIDS and TB HCUs. She explained that because they don't do counselling, medication, or discuss the x-rays with HCUs, they have very limited communicative interaction with HCUs.

At Mary Malahlela Hospital I spoke with two physiotherapists in their community service year. They were both interested in the resources, and said that this was the first time they had seen resources like this and that they believed they could be very helpful. They suggested that resources such as those included in this study could be introduced to HCPs from the university level, as in their experience this was the first time they experienced healthcare communication barriers and when they first thought about communication, particularly when they first started seeing HCUs. To try bridge the communication barriers they would often act things out, which reflects the deictic communication described by Anthonissen and Sobane (2013: 270–271). However, they also did not participate due to the focus of the flashcards not covering what they would need. They took time to look through the resources and noted that they are very medicine-oriented, while for physiotherapy they would need pictograms for actions. Despite this, they were enthusiastic about the study as they explained that they regularly face communication barriers as neither of them could speak isiXhosa. In order to bridge these communication barriers they would often ask a nurse to interpret; however, this also had challenges as they explained that they would not ask a nurse to interpret if they did not have a good relationship with them.

d) Participatory Action Research

The initial plan for this research was to have a more participatory approach to the development of the resources. Not being able to implement the research in this way led to certain HCPs choosing not to participate because the resources were not sufficiently suitable for their specific work. On the other hand, having tangible resources that could be showed to potential participants had a positive effect on recruiting participants, as evidenced by participants looking through the resources themselves, giving positive feedback on them, and then choosing to participate. This also minimised the commitment needed to participate in the study, compared to 'starting from scratch'. In order to reach a maximum number of HCPs, such an intervention should begin with presentable resources and also include a more detailed participatory section involving highly motivated participants to develop and/or adapt the resources based on the participants, rather than participants self-selecting based on what the resources cover.

Most of the participants recruited for the study were from Lindiwe Sidali Hospital. There were several reasons for this. One reason was the institutional focus on and interest in research. After I explained the study to the head of Family Medicine and asked whether he and his team would be interested in participating, he responded with, "I am going to say yes, and the reason I'm saying yes is because we encourage research at this hospital." It was not clear to me whether encouraging research was the only reason he was saying yes, or whether he was interested in this study specifically, or a combination of these factors. Either way, his interest in research and the institutional support for research was favourable for the recruitment of participants at this site.

Another case where interest in research and the study design played a positive role in the recruitment of participants was at Ncumisa Jilata Hospital (a control site). The Head of Infectious Diseases at Ncumisa Jilata was particularly interested in the study design, and when I met with him and the Doctor of Infectious Diseases, we discussed the study protocol in detail and they looked through the questionnaire booklets in detail. Illustrating the benefits of a participatory approach, they suggested that the questionnaire should also collect information with the headings 'my language', 'language of the consultation' and 'patient's language’. Participants have valuable insight into what information would be useful to add context or to better understand the data that is collected.

As Ncumisa Jilata was one of the last sites that I visited, and as such other participants had already received their questionnaires, it was not possible to make this change in the printed booklets and questionnaires, so instead participants were asked to note the L1 of the HCU (if known) and any other relevant language information in the margin. Adding this in later led to missing data, but also allowed a more detailed picture of the participants and the HCUs they consulted.

Similar to other meetings with HCPs, they also asked if the study was focusing specifically on where there is a language barrier or not. I explained that the study was looking at improving communication and not specifically restricted to language barriers, so they decided to take six questionnaire booklets with the aim of recruiting three doctors and three nurses.

They believed that the resources (both the flashcards and the app) would be useful, particularly the symptoms pack which they said would be very helpful, especially for chronic care but also for acute care. The Head of Infectious Diseases then asked if the study was specifically focusing on chronic or acute care, and since the study did not have a particular focus on either of those, he suggested that at this site we focus on chronic care because it would be the context in which the study would be easiest to implement, and where it would be most appropriate.

The original aim of the pilot feasibility trial was to only include HCPs providing consults for HIV/AIDS and/or TB specifically, but was extended to include consultations for co-infections in order to recruit more participants and because at most sites this would have been more difficult to monitor. However, at Ncumisa Jilata they decided to only recruit HCPs who work specifically with HIV/AIDS and TB, but not necessarily with co-infections, which was possible due to the setup of the hospital and thanks to the oversight of the Head of Infectious Diseases.

Both HCPs also asked about the difference in answers between the control and intervention groups, specifically what differences I was expecting to see. The Head of Infectious Diseases agreed that we would not expect to see notable differences across the three questionnaires, and Doctor of Infectious Diseases also noted the potential for change by virtue of participating in a health communication study, and for that change to be reflected in the questionnaires.

In some cases, for example in clinical trials, it may not be desirable to have participants' input in the design and implementation of the study, or their knowledge and expectation of traditional Eurocentric research methods. However, in the implementation of this study the benefits of using a PAR approach were clear. While one of the more obvious benefits of a PAR approach is the participants' detailed knowledge of the sample group, another benefit can be – depending on the participants and their context – their familiarity with research methods. When conducting PAR with HCPs, it can be expected that many of them will be familiar with traditional research methods. In the case of this research, this helped to improve the research because the structure of the pilot feasibility trial was (generally) easily understood, and participants were able to advise how best to implement the protocol in the context of their site. This is particularly helpful when conducting interdisciplinary research, and when incorporating a decolonial approach, as it opens up possibilities for new ways of doing and understanding.

e) Communication barriers vs language barriers

In the needs analyses (detailed in Chapter 5) it was found that HCPs had different views on who was responsible for communication in consultations. Related to this, it was found that HCPs also had different views on what constitutes communication, and who could encounter communication barriers. Through our various meetings at Lindiwe Sidali Hospital, when we met with groups of HCPs consisting both of people who spoke isiXhosa as L1 and those who did not, it was always only those who did not speak isiXhosa who showed interest in the study. But when meeting with groups where everyone spoke isiXhosa, for example in our meeting with all the nursing heads, the focus shifted from an assumption that communication equated language towards a focus on clearer communication between HCPs and HCUs. In this case it was clear from the outset that the research was not aimed only at some HCPs and not others, based on language.

A future intervention of this type would benefit from clarifying the concepts of 'communication' and 'language barrier' when introducing the research, to clarify which of these are addressed in the research and therefore at which HCPs the research is targeted.

To clarify that the focus in this case was on clearer communication rather than language barriers, I presented the flashcards and mentioned the app, but acknowledged that there was probably no-one there who would need the app to translate, except perhaps in the case of needing to translate to other South African languages. When presenting the flashcards there was emphasis on not replacing communication, and the helpfulness of visual aids was explained. The Head of Nursing Development then expanded that she could see that the resources were to enhance communication. The Head of Nursing then said that he thought the resources could be useful for Paediatrics, Family Medicine, and maybe A&E. The Head of Nursing in Mental Health was enthusiastic about the resources; he told me that he really liked the resources, and agreed that they would be helpful for the Family Medicine department. The Head of Nursing Development was also very interested in the study, even though she would not be participating.

In order to try to mitigate a repeat of the situation where the HCP said she couldn't say no because her boss was there, I explained in the meeting with the Nursing managers that if people did not choose to participate it would be very helpful for the study if they could tell us a clear no and simply share whether the resources would not be helpful, or if they do not need support with communication, making sure that this was clear to the supervisor too.

f) Nursing departments

The Head of Paediatric Nursing was also interested in participating in the study, but ultimately her department did not end up participating. She passed on the contact details of the Sister in Charge so that we could contact her ourselves; a different approach to the Rehab Unit and Family Medicine Department where we had been introduced to the HCPs by the relevant HoD.

Not being accompanied by the relevant Heads when we approached the Sisters in Charge had a relatively adverse effect on recruitment; while we had the contact details for the Sister in Charge at Family Medicine, it was not possible to reach her, and the research assistant returned to the hospital several times to try and meet her, but she was not available. It was also not clear to me whether she was present when I presented the research to the Family Medicine department, but she did not opt in to speak to me afterwards. Similarly, it took several visits before the research assistant was able to speak with the Sister in Charge at

Paediatrics, and when she did speak with her the apparent power dynamics of the Doctor present with her had an effect on the Sister in Charge's perceived enthusiasm for the study. However, I then contacted the Sister in Charge myself to discuss the study and she was happy to participate together with her nursing team. She suggested making a WhatsApp group with her team and I to discuss the research; however, the group had not been formed by the time the fieldwork was concluded and unfortunately this avenue was not explored further. In this case it is possible that the WhatsApp group would have been a fruitful means of conducting this research; however, not being able to meet earlier and not being present at the site in the beginning phases to set this up resulted in the delays.

As a result of the conflation of communication barriers with language barriers, and of different approaches to being introduced and the resulting delays or inaccessibility of potential participants, regrettably no nurses at hospitals were included in this study. The one nurse who participated in the study is a nurse at the NGO clinic and speaks Afrikaans as her L1, and thus is not representative of most nurses who work at government-funded clinics and hospitals in South Africa. This means that the study reflects a narrower selection of HCPs, and is a limitation of this study. Recommendations for future interventions are that the scope of the study should be explained clearly with the expectation that communication and language could be conflated, and with care taken to be introduced by relevant people in order to meet and recruit other HCPs. It is commonly documented in the literature and the data presented in this study that nurses play a significant role in interpreting at healthcare sites, this was not sufficiently taken into account in the structuring of the study. If nurses are to be included in a future trial (as indeed they should be), the study would benefit from tailoring their participation to include exploring their dual role as both primary communicators and as interpreters for other HCPs.

7.4. Ancillary analysis: Resources feasibility

The feasibility of the resources is discussed here using a mixed methods approach.

7.4.1. Quantitative data presentation: Communication scale

The questionnaire used comprised a scale to measure communication between HCPs and HCUs. Related to the question "To what extent do you agree or disagree with the following statements?", the statements included were:

1. I am able to communicate effectively with this patient.
2. This patient is able to communicate effectively with me.

3. I have the resources I need to communicate effectively in this consultation with this patient.
4. The relationship between me and this patient is good.
5. My patient trusts the advice I give them.
6. My patient trusts the treatment I give them (if applicable).

This six-item scale also comprised three subscales: Q1 and Q2 form a subscale on communication, Q3 measures access to resources, and Q4, Q5 and Q6 form a scale on trust.

Cronbach's alpha[12] was calculated for all six items together, and for the subscales of communication and trust. The scale reliability coefficient for all six items as one scale was 0.8959, which can be considered acceptable to excellent. The subscale of trust consists of Q4, Q5 and Q6 and has a Cronbach's alpha of 0.9248.

These scale reliability coefficients indicate that the scale and subscales are very reliable, and given that they have been validated through this pilot feasibility trial they may be appropriate to be used for future studies.

7.4.2. Summary statistics

a) *Descriptive statistics for the main trial outcome measures*

	Control group			**Intervention group**		
	Obs.	Mean	SD	Obs.	Mean	SD
T1	20	4.163333	.5233607	64	3.533854	.7790125
T2	20	3.626667	.7232642	44	3.712121	.7430676
T3	16	3.947917	.8601438	32	3.807292	.8307588

The intervention began with five HCPs in control group, and 16 HCPs in the intervention group. At T1 (which was before the intervention group began using the resources), HCPs in the control group scored an average of 4.16 (SD = .52) on the 5-point scale measuring communication and trust, while those in the intervention group scored 3.53 (SD = .78), suggesting that at this point in time the HCPs in the intervention group self-reported greater

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[12] Cronbach's alpha measures how consistent the variance within the scale is (i.e. its internal consistency), and can be interpreted as a reflection of how reliable the scale is (Brown, 2002: 17). A Cronbach's alpha between 0.70 and 0.90 is usually regarded as acceptable (Tavakol and Dennick, 2011: 53).

communication and trust between them and the four HCUs they had recently consulted, as compared to the self-reported scores of the HCPs in the control group. At T2, one month after the intervention group had been using the resources, five HCPs in the control group and 11 HCPs in the intervention group completed the questionnaire again, reporting on their past four consultations. At this point both groups showed similar scores and variance: 3.62 (SD = .72) in the control group and 3.71 (SD = .74) in the intervention group. These scores indicate a drop in trust and communication in the control group, with a small increase in the intervention group. At T3, after the intervention group had been using the resources for two months, four HCPs completed the questionnaire for the control group, and eight HCPs completed the questionnaire for the intervention group. Here we see a small increase across both groups, to 3.95 (SD = .86) for the control group and 3.81 (SD = .83) for the intervention group. This suggests that HCPs in both groups experienced greater communication and trust between them and the HCUs they had recently consulted at that time.

b) Communication between HCPs and HCUs

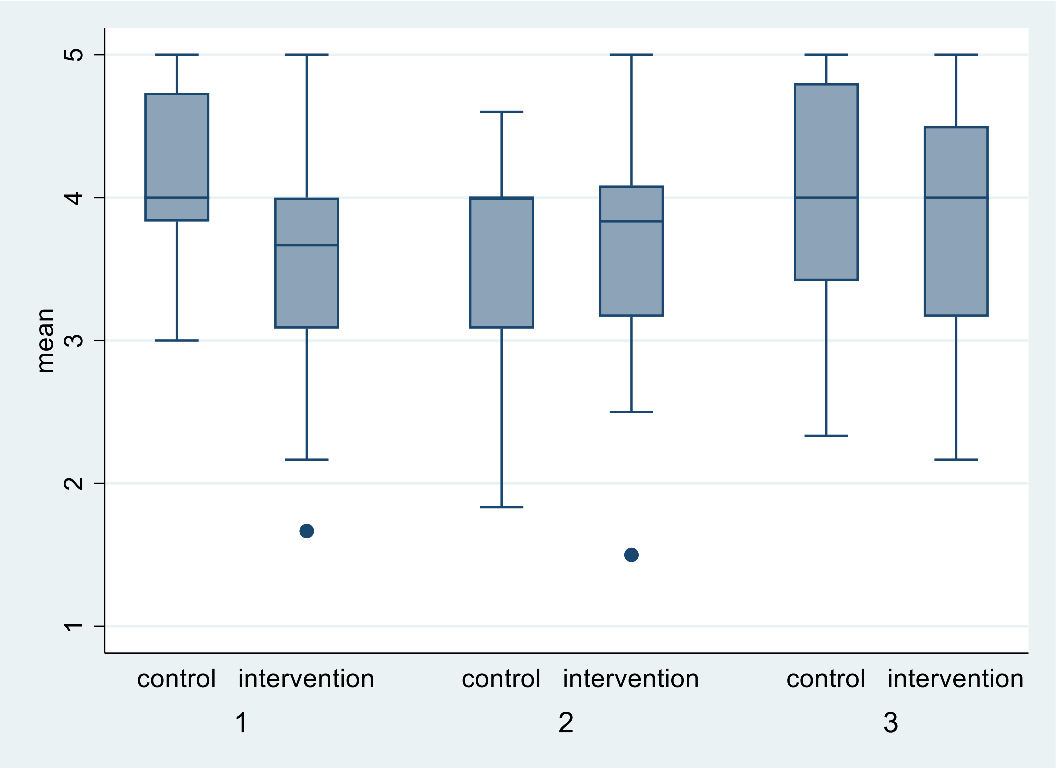


Table 3: Mean of the scale

The summary statistics presented above are visualised in Table 3 above. A small increase in the mean of the intervention group can be observed from T1 to T2 to T3, while the control group shows a lowered score at T2, and then returns at T3 to a score similar to the control group at T1, and the intervention group at T3.

These results are presented per question below, where a similar pattern can be observed.

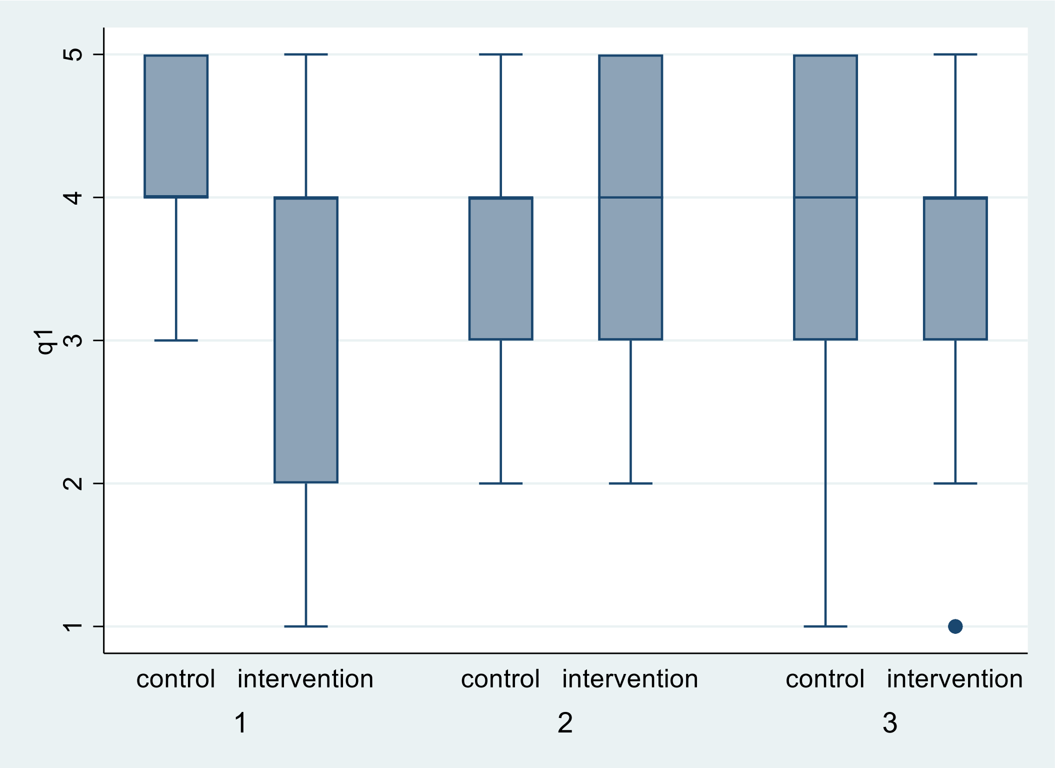


Table 4: Question 1: I am able to communicate effectively with this patient

When considering their communication with the HCU, HCPs in the control group scored highly at T1 and T3 (albeit with notable variance at T3), with a slight drop at T2. The HCPs in the intervention group showed greater variance at T1, scoring their ability to communicate with the HCUs in a middle range. This increased at T2, and remained higher at T3 (although not as high as at T2).

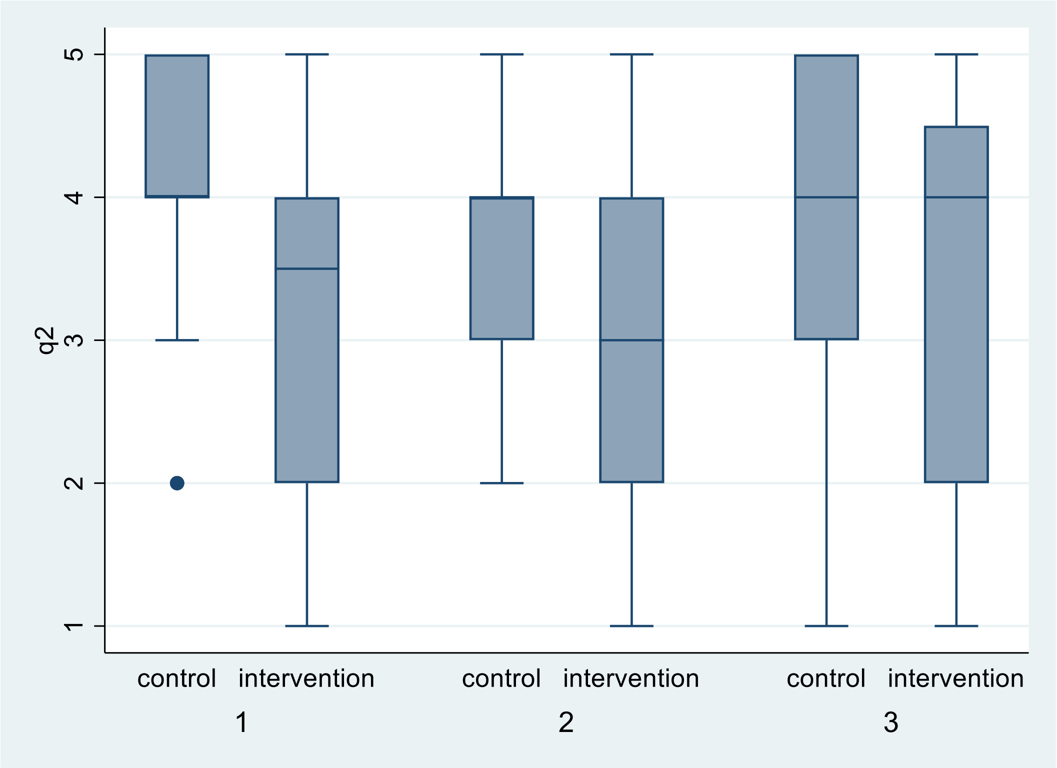


Table 5: Question 2: This patient is able to communicate effectively with me

HCPs’ perceptions of the HCUs’ ability to communicate with them largely reflected their self-reported communication abilities seen in Question 1. When compared to their responses in Q1 those in the intervention group scored slightly lower on average at T2, and with greater variance at T3.

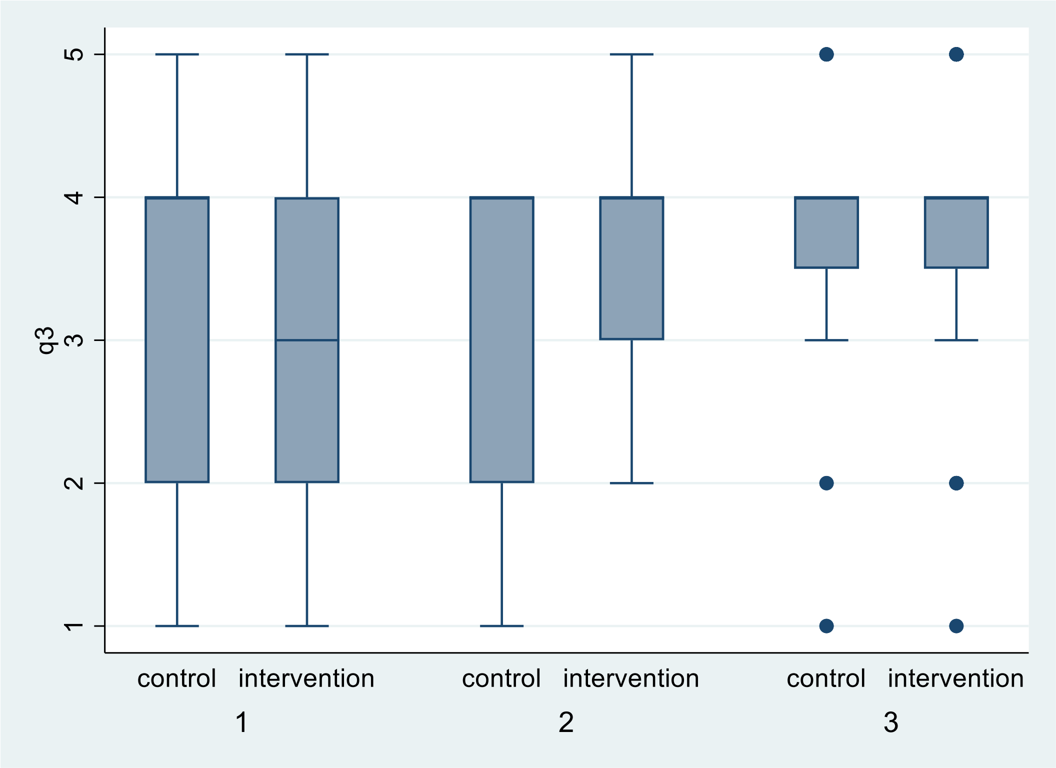


Table 6: Question 3: I have the resources I need to communicate effectively in this consultation with this patient

When considering the communication resources they have available, HCPs in both groups showed increasing scores from T1 to T2 to T3 (although only those in the intervention group had access to the *Healthy Talk* resources). A greater increase was seen from T1 to T2 among the intervention group, and outlier scores appear at T3 for both groups.

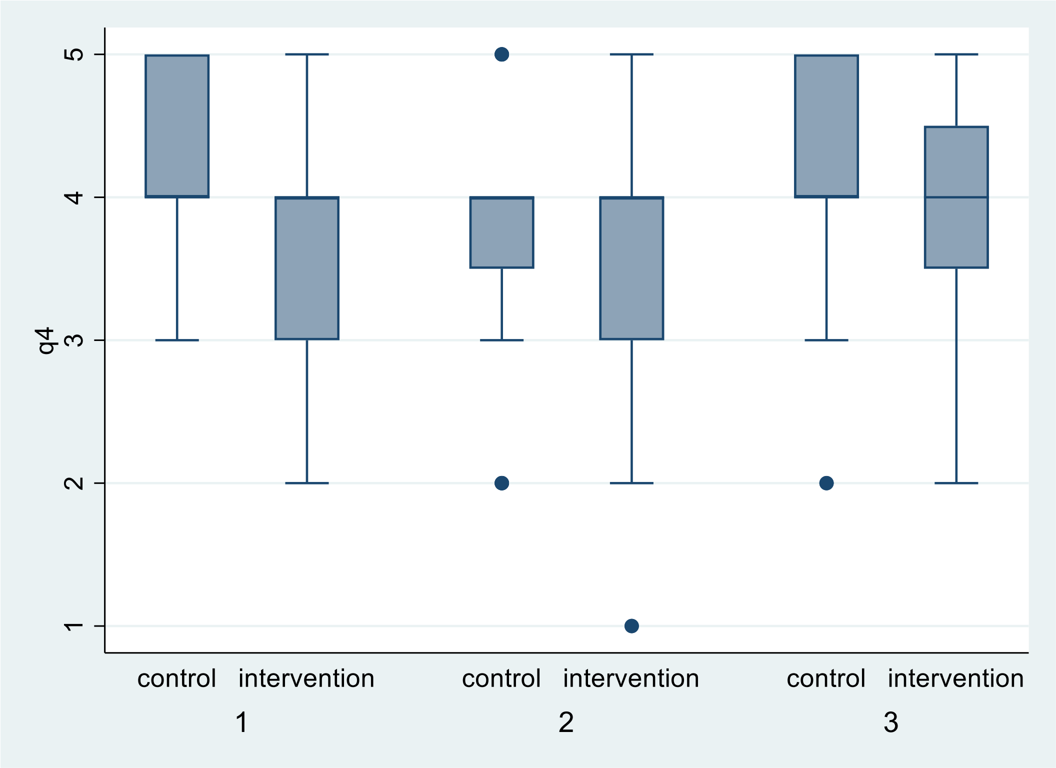


Table 7: Question 4: The relationship between me and this patient is good

Similar to the trend observed for Questions 1 and 2, a high-lower-high trend can be observed in the control group when considering the HCP-HCU relationship. While no difference can be observed in the intervention group from T1 to T2, HCPs self-reported scores of a positive HCP-HCU relationship increase from T2 to T3.

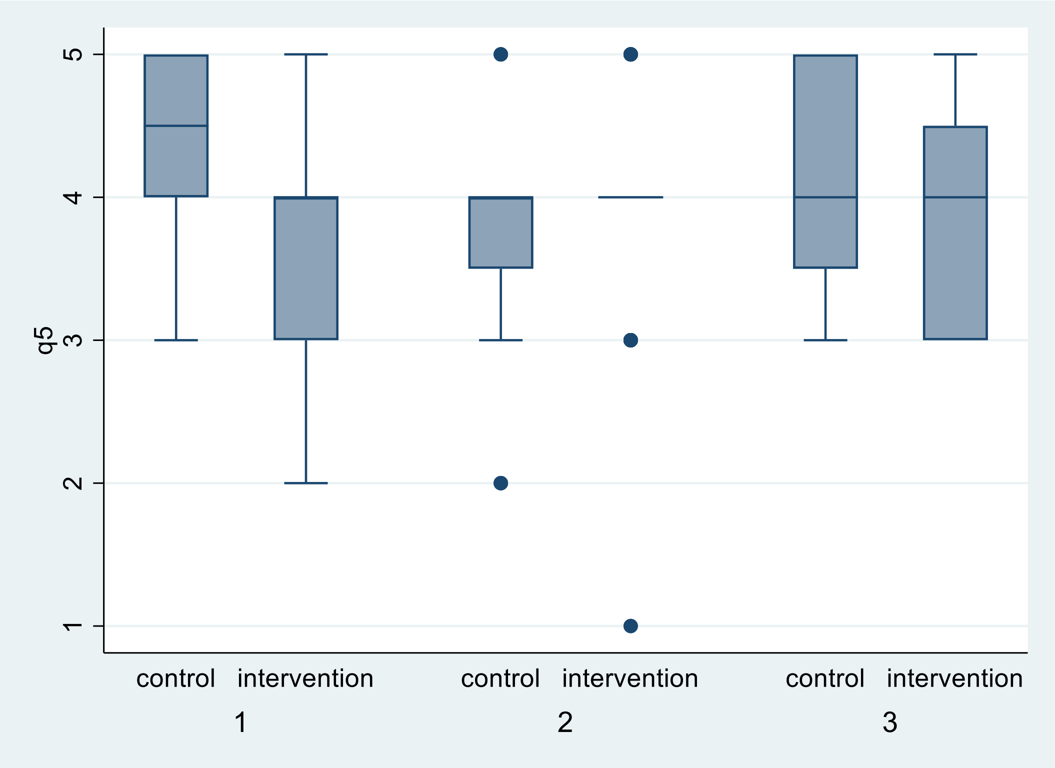


Table 8: Question 5: My patient trusts the advice I give them

HCPs’ reports of the trust HCPs have in their advice shows a lot of variance across both groups. The control group shows high scores for trust at T1, mid to high scores at T2, and a high score again at T3, albeit with greater variance and a lower median than that at T1. In the intervention group a small increase in perceived trust can be seen from T1 to T2 to T3, although there is a great amount of variance at T2.

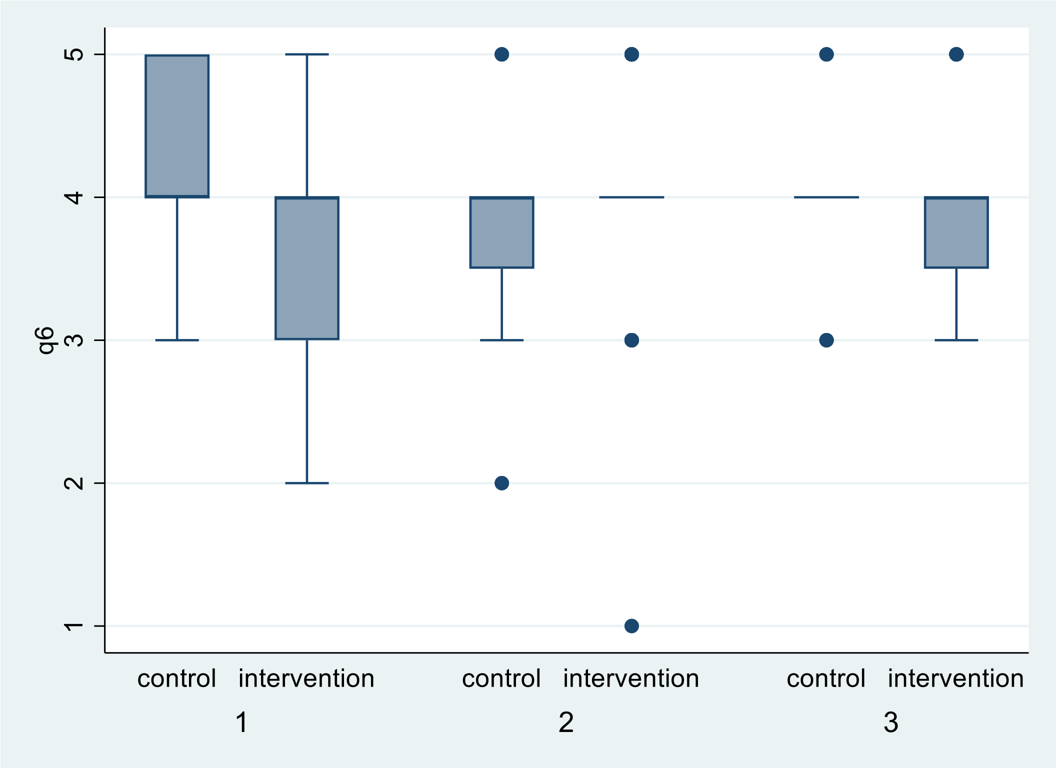


Table 9: Question 6: My patient trusts the treatment I give them

In cases where HCPs provided treatment for the HCUs, they self-reported the HCU's perceived trust of this treatment. This pattern reflects those described for Question 5 above, with greater variance in the control group at T3.

The above tables illustrate very marginal increases in the intervention groups, and similar trends in the intervention and control groups. Overall, the common lower scores at T2 followed by higher scores at T3 could be considered in line with Hulsman's (2009: 305) assertion that communication behaviours are built from learnt and practised actions. In this case one might expect a dip in communication outcomes while a new skill or resource is being learnt, and an increase once this new skill has been acquired. If this is indeed the case, these results would suggest the successful impart and uptake of new cognitive scripts. However, since a similar trend is seen in the control group, it is possible that external factors affected the communication and trust measured here. This will be further analysed in the quantitative data analysis section using repeated measures ANOVA and linear mixed models.

c) Subscales

These questions can be considered in terms of two subscales, with questions 1 and 2 comprising a subscale on communication, and questions 4, 5 and 6 comprising a subscale of trust. As question 3 is a standalone question regarding resources, this is not included as a subscale. The scores of these two subscales are depicted in the tables below.

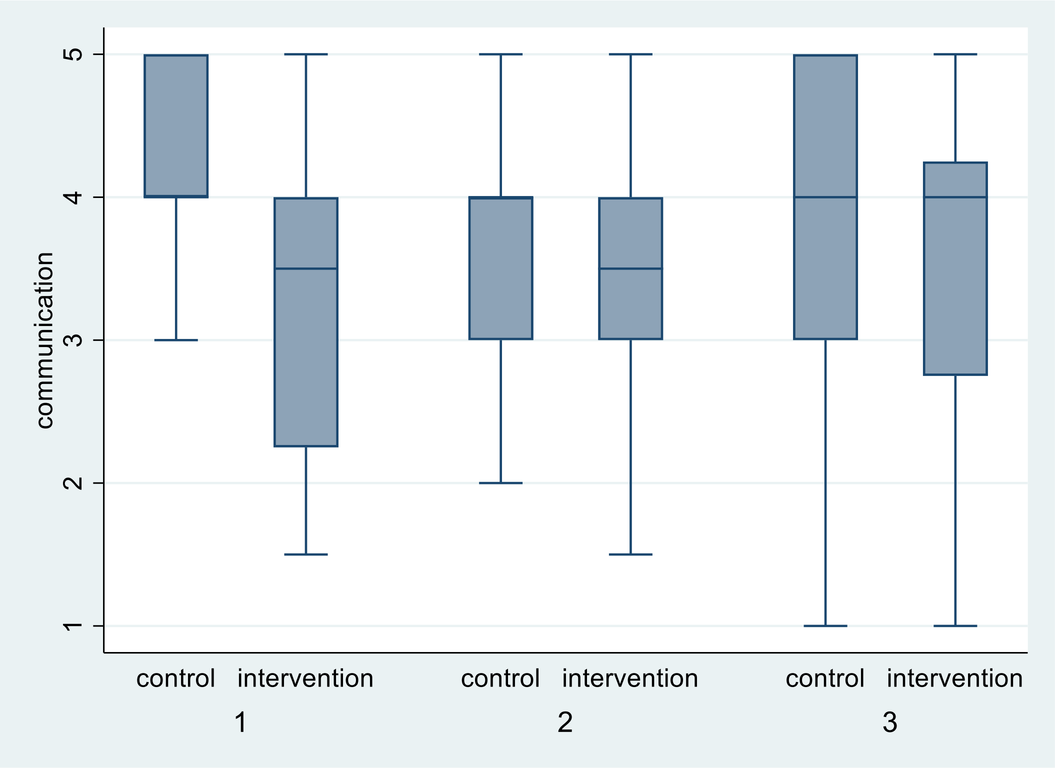


Table 10: Communication subscale

The communication subscale reflects the overall scores for this questionnaire, with the control group showing high scores at T1 and T3 and mid to high scores at T2. The intervention group shows a similar median score at T1 and T2, with higher scores in the lower quartile at T2, and a higher score at T3.

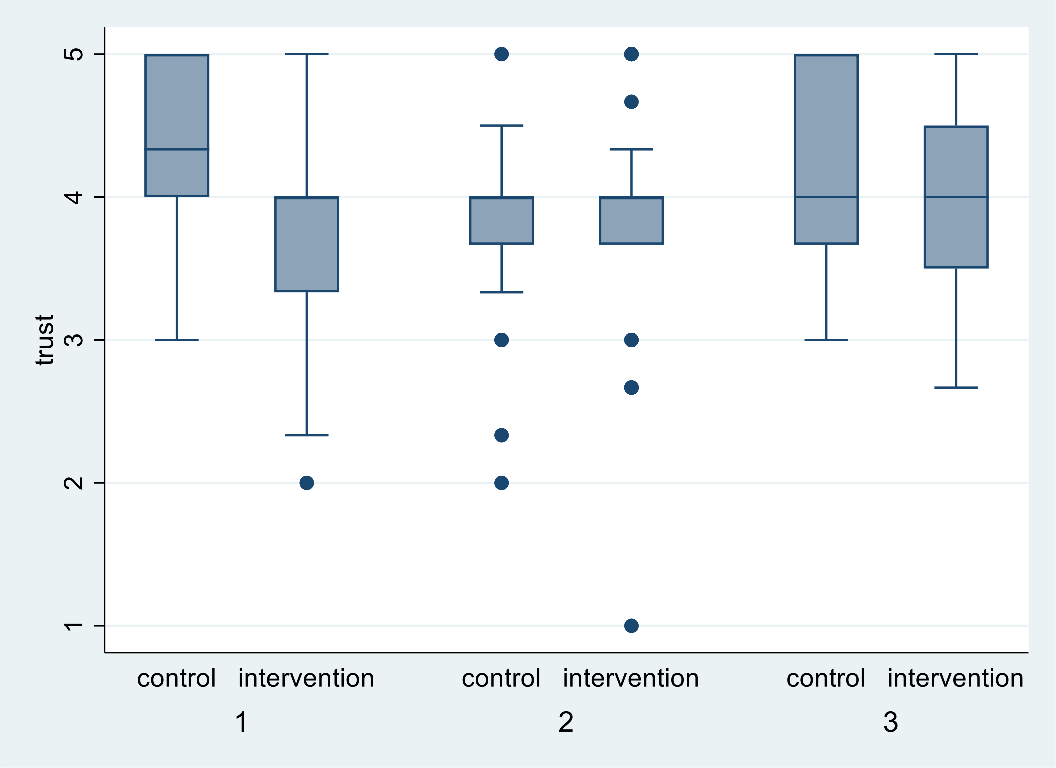


Table 11: Trust subscale

In the trust subscale the control group again shows high scores at T1 and T3 (although slightly lower scores at T3), and mid to high scores at T2, with many outliers. In the intervention group small increases can be seen from T1 to T2 to T3, with many outliers present at T2 with this group too.

d) How often the resources were used

The HCPs in the intervention group reported how often they had used the resources at T2 (after one month of having access to the resources and training) and at T3 (after two months).

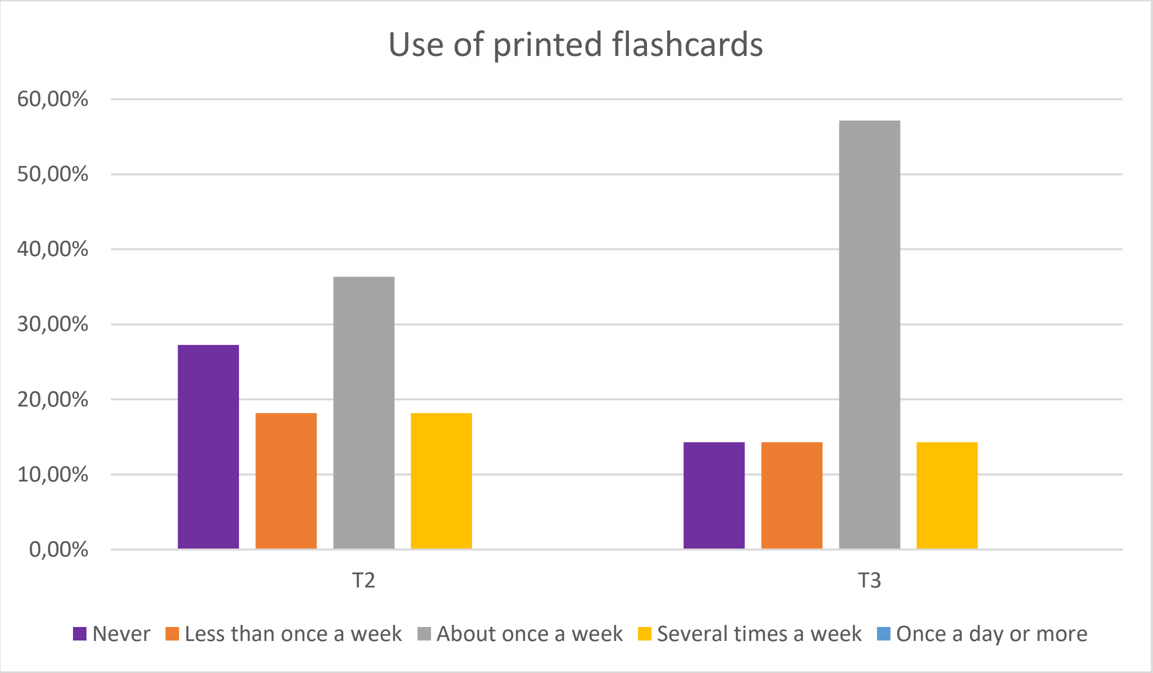


Table 12: Use of printed flashcards

At T2, about 36% of HCPs were using the printed flashcards about once a week, while about 27% never used them, and 18% used them less than once a week or several times a week. After another month, at T3, more than half of the participating HCPs (57%) were using the resources about once a week, with about 14% using them several times a week, less than once a week, or never. This illustrates that the printed flashcards were most commonly used about once a week, and increasingly so after a longer period of access.

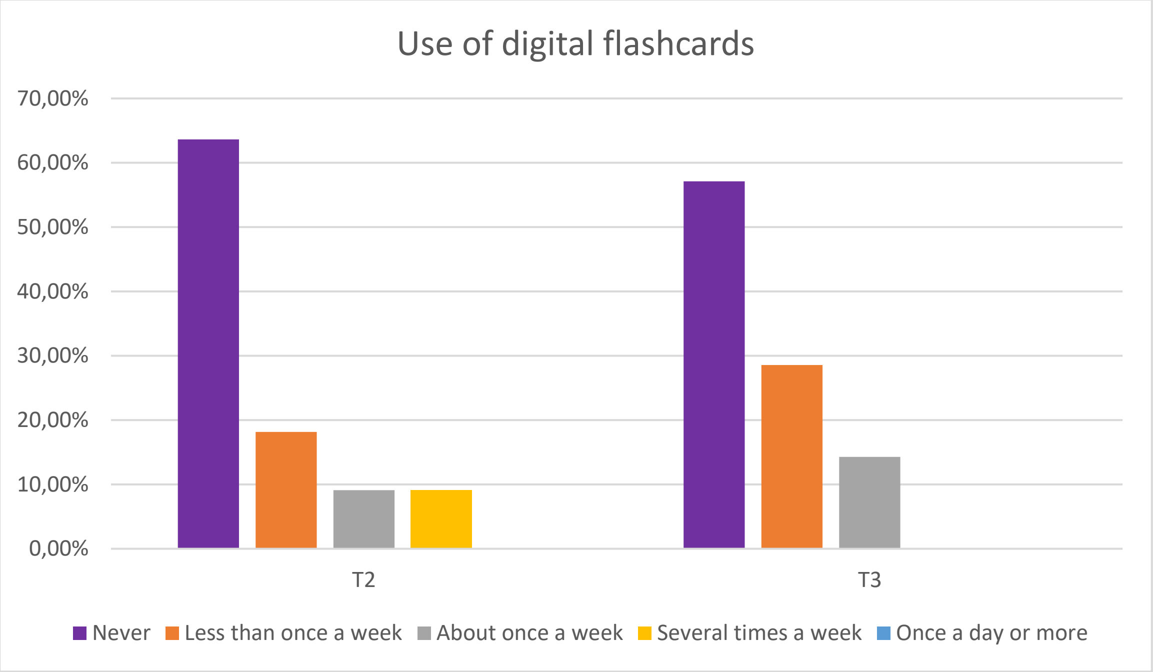


Table 13: Use of digital flashcards

At T2, about 63% of HCPs were not using the digital flashcards, with about 18% using them less than once a week, and 9% using them once a week or more. At T3, most HCPs (57%) still did not use the digital flashcards, 28% used them less than once a week, and 14% used them about once a week. It can therefore be observed that, although the digital flashcards were used by a few HCPs, the printed flashcards were more commonly and more regularly used than the digital flashcards.

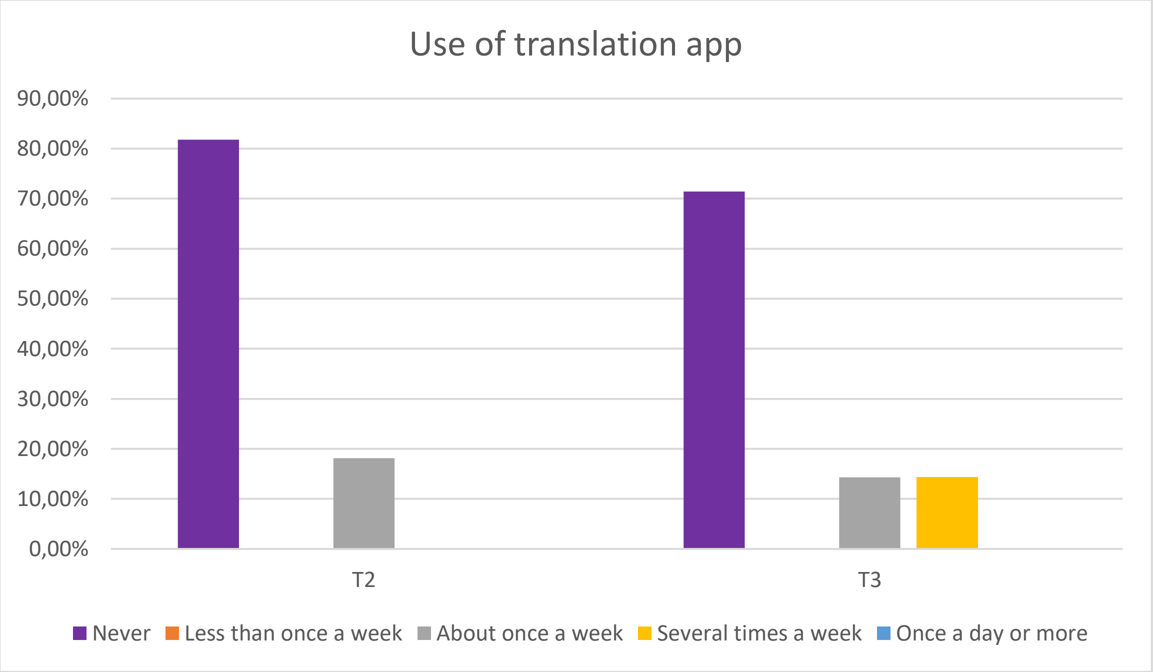


Table 14: Use of translation app

At T1 only about 18% of participating HCPs had used the translation app about once a week; the others (about 82%) had not used it at all). After another month, at T2, the app was used several times a week by about 14% of HCPs, and about once a week by another 14% of HCPs, with the remaining HCPs still not using the app at all.

It can therefore be observed that the printed flashcards were the most commonly and most often used resource by the HCPs in the intervention group.

7.4.3. Quantitative data analysis

Baseline differences were found between the control and intervention groups.
All variables were significantly and highly correlated at T1.

a) Correlations

The correlations depicted below reflect the subscales of communication and trust, with stronger correlations between Q1 and Q2, and Q4, Q5 and Q6. Reflecting the anomaly of the control group at T1, there are small negative correlations between Q3 and Q5, and Q3 and Q6.

T1: control group

```
             |       q1       q2       q3       q4       q5       q6
-------------+------------------------------------------------------
          q1 |   1.0000
          q2 |   0.6649   1.0000
          q3 |   0.4035   0.5519   1.0000
          q4 |   0.4037   0.2845   0.2268   1.0000
          q5 |   0.2163   0.1883  -0.1072   0.6078   1.0000
          q6 |   0.2163   0.1883  -0.1072   0.6078   1.0000   1.0000
```

T1: intervention group

```
             |       q1       q2       q3       q4       q5       q6
-------------+------------------------------------------------------
          q1 |   1.0000
          q2 |   0.7980   1.0000
          q3 |   0.7552   0.6706   1.0000
          q4 |   0.5880   0.6248   0.5003   1.0000
          q5 |   0.5724   0.5819   0.4572   0.8028   1.0000
          q6 |   0.4737   0.4633   0.3653   0.7094   0.7445   1.0000
```

T2: control group

```
             |       q1       q2       q3       q4       q5       q6
-------------+------------------------------------------------------
          q1 |   1.0000
          q2 |   0.7328   1.0000
          q3 |   0.4962   0.3098   1.0000
          q4 |   0.6730   0.7457   0.4377   1.0000
          q5 |   0.6730   0.7457   0.4377   1.0000   1.0000
          q6 |   0.6894   0.7062   0.3189   0.8682   0.8682   1.0000
```

T2: intervention group

```
             |       q1       q2       q3       q4       q5       q6
-------------+------------------------------------------------------
          q1 |   1.0000
          q2 |   0.6249   1.0000
          q3 |   0.5177   0.6309   1.0000
          q4 |   0.5866   0.5199   0.4445   1.0000
          q5 |   0.5254   0.5553   0.4353   0.8570   1.0000
          q6 |   0.5491   0.5044   0.4356   0.8784   0.9783   1.0000
```

T3: control group

```
             |       q1       q2       q3       q4       q5       q6
-------------+------------------------------------------------------
          q1 |   1.0000
          q2 |   1.0000   1.0000
          q3 |   0.7193   0.7193   1.0000
          q4 |   0.8165   0.8165   0.7637   1.0000
          q5 |   0.4668   0.4668   0.2357   0.4046   1.0000
          q6 |   0.4598   0.4598   0.2589   0.5417   0.8402   1.0000
```

T3: intervention group

```
             |       q1       q2       q3       q4       q5       q6
-------------+------------------------------------------------------
          q1 |   1.0000
          q2 |   0.9303   1.0000
          q3 |   0.8936   0.8449   1.0000
          q4 |   0.5916   0.6068   0.4858   1.0000
          q5 |   0.5751   0.6364   0.5161   0.8272   1.0000
          q6 |   0.6123   0.6045   0.5495   0.8255   0.9392   1.0000
```

Two-sided t-tests with unequal variances were conducted for T1 to determine baseline differences. There were significant differences for Q1, Q2, Q4, and Q5, as detailed below:

t-tests for baseline differences

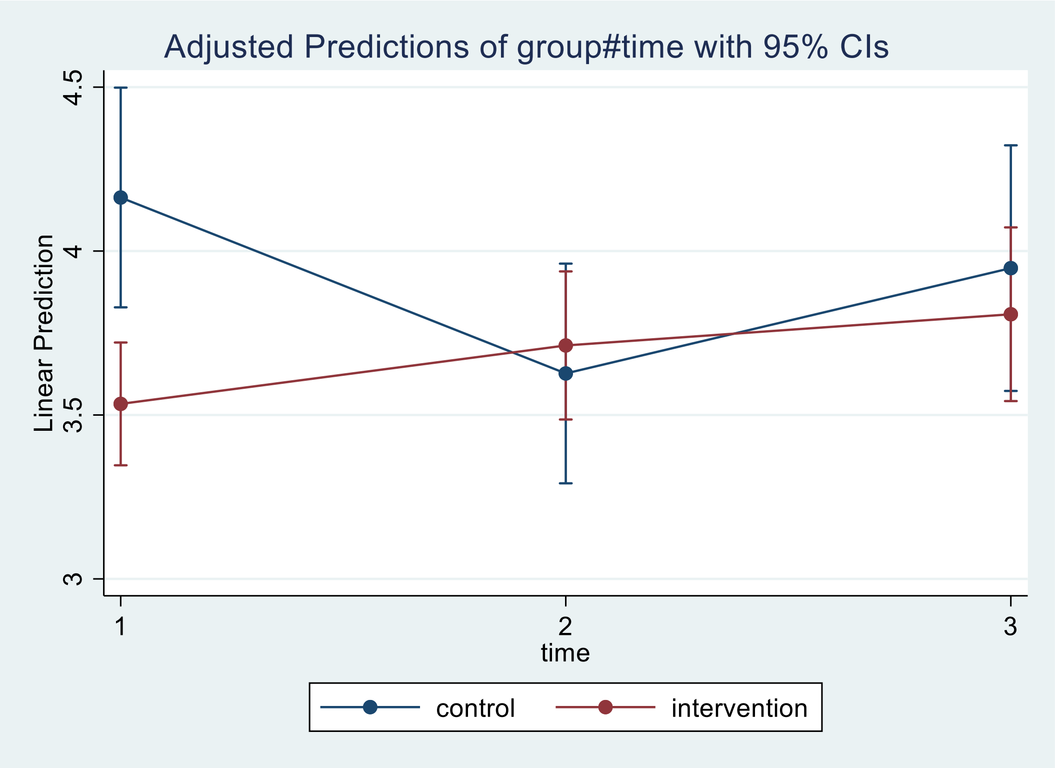
	Mean	**SD**	***t* test**	***p* value**	**Effect size**
Question 1			*t*(66.746) = 4.12	< 0.001	0.75
Control group	4.3	0.57			
Intervention group	3.5	1.16			
Question 2			*t*(47.622) = 3.57	< 0.001	0.75
Control group	4.1	0.79			
Intervention group	3.28	1.17			
Question 3			*t*(30.0353) = 0.76	0.452	0.2
Control group	3.4	1.19			
Intervention group	3.17	1.1			
Question 4			*t*(34.6566) = 3.94	< 0.001	0.96
Control group	4.35	0.67			
Intervention group	3.66	0.74			
Question 5			*t*(40.1002) = 4.12	< 0.001	0.93
Control group	4.45	0.61			
Intervention group	3.77	0.77			
Question 6			*t*(26.2318) = 2.78	0.009	0.71
Control group	4.31	0.6			
Intervention group	3.8	0.7			

This means that there was a statistically significant difference between the control and intervention group's self-reported ability to communicate with their HCUs (Q1); for their HCUs to communicate with them (Q2); the relationship between the HCP and HCU (Q4); HCUs' trust of the advice given by the HCP (Q5); and HCUs' trust of the treatment prescribed by the HCP (Q6). Interestingly, there was no statistically significant difference between HCPs' access to the communication resources they needed to communicate in their consultations (Q3). This illustrates the scarcity of healthcare communication resources.

b) Repeated measures ANOVA

A repeated-measures ANOVA was used to compare the means for the scale and for each question between the intervention and control groups over time.

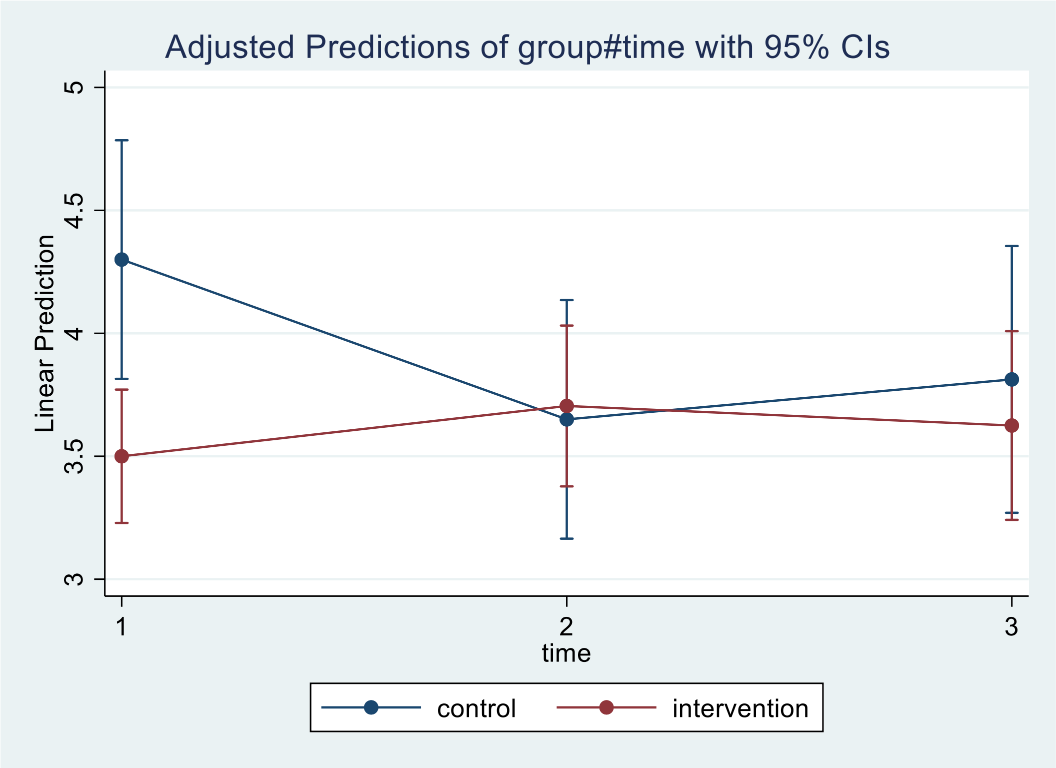
Mean of the scale



While there was no statistically significant difference between the two groups' scores, there was a small trend (*p* = 0.037) in the group by time interaction, with no effect size detectable (0.03).

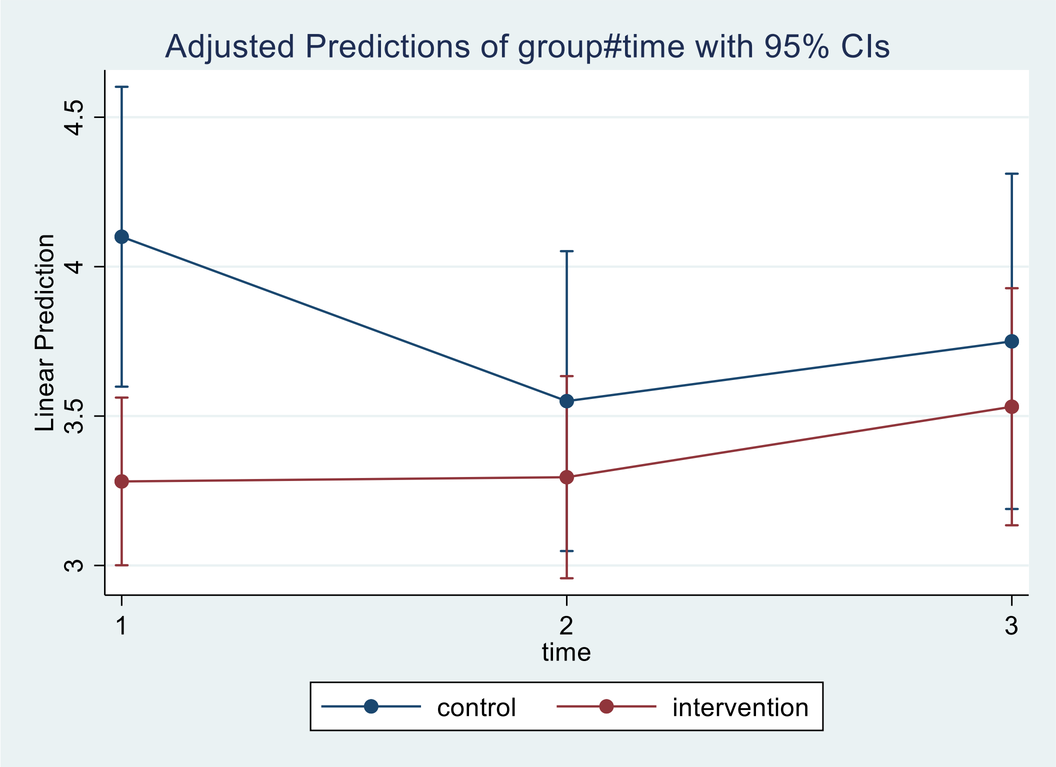
Results for the individual items were very similar.

Question 1: I am able to communicate effectively with this patient



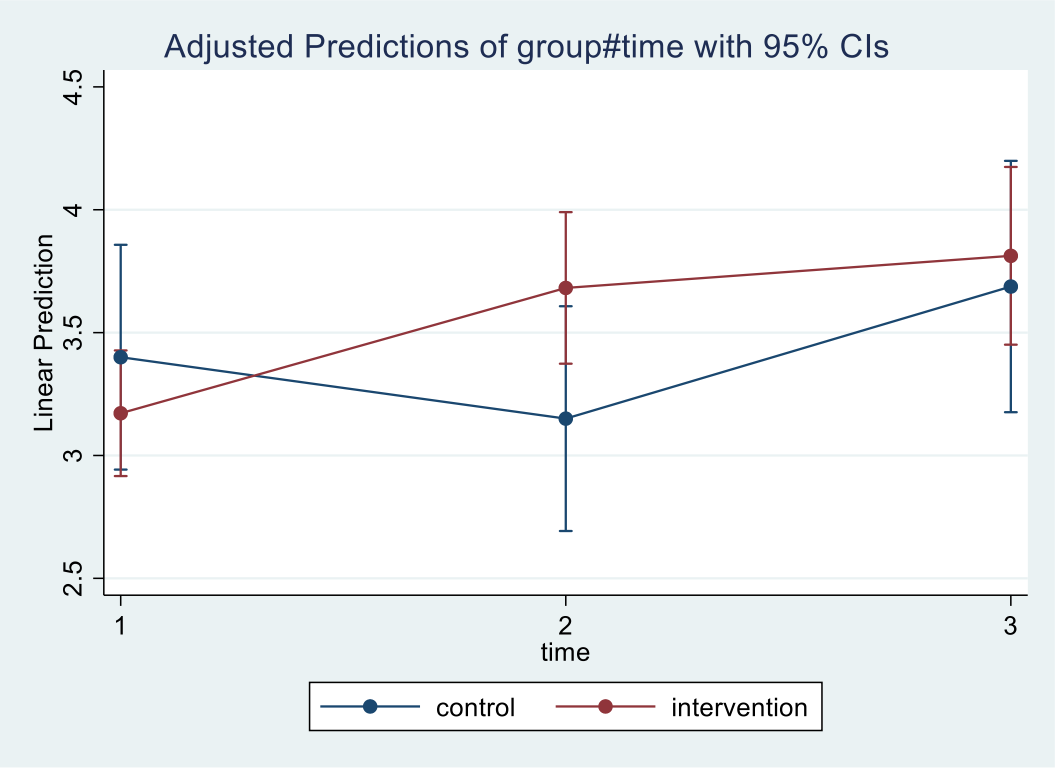
There was no statistically significant difference between the two groups' scores in the group by time interaction (*p* = 0.1011), with no effect size detectable (0.02). There was a small trend in the group interaction (*p* = 0.0799), also with no detectable effect size (0.02).

Question 2: This patient is able to communicate effectively with me



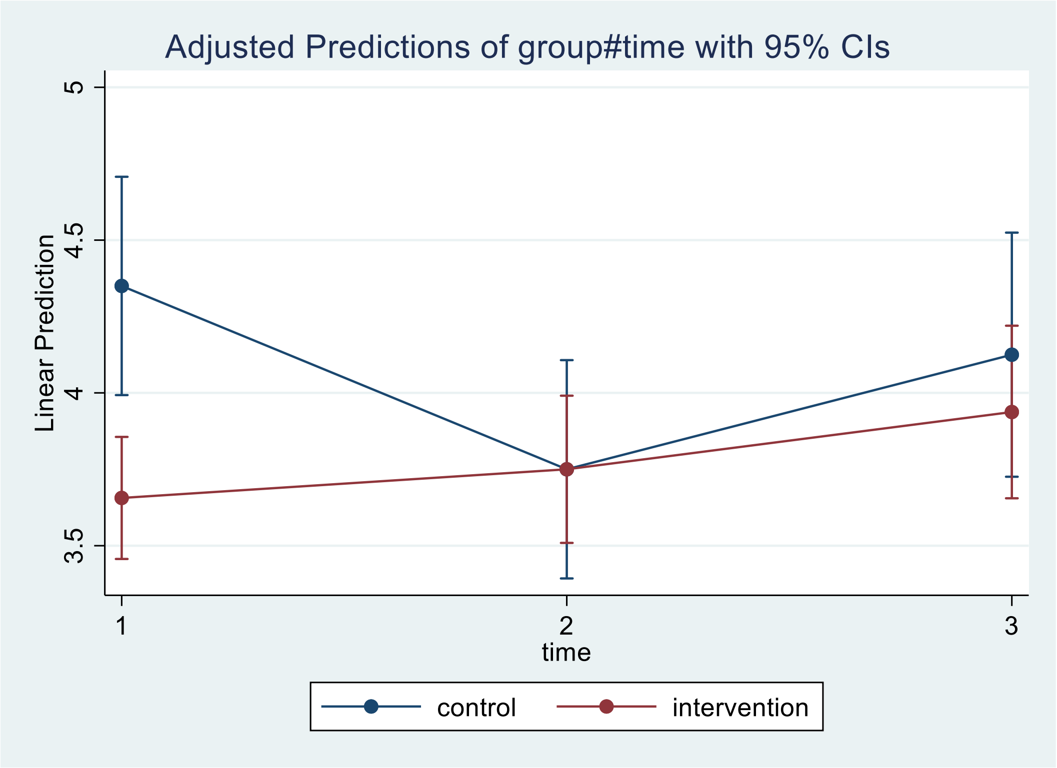
There was no statistically significant difference between the two groups' scores in the group by time interaction ($p = 0.2969$), with no effect size detectable (0.02). There was a small trend in the group interaction ($p = 0.0194$), similarly with no detectable effect size (0.03).

Question 3: I have the resources I need to communicate effectively in this consultation with this patient.



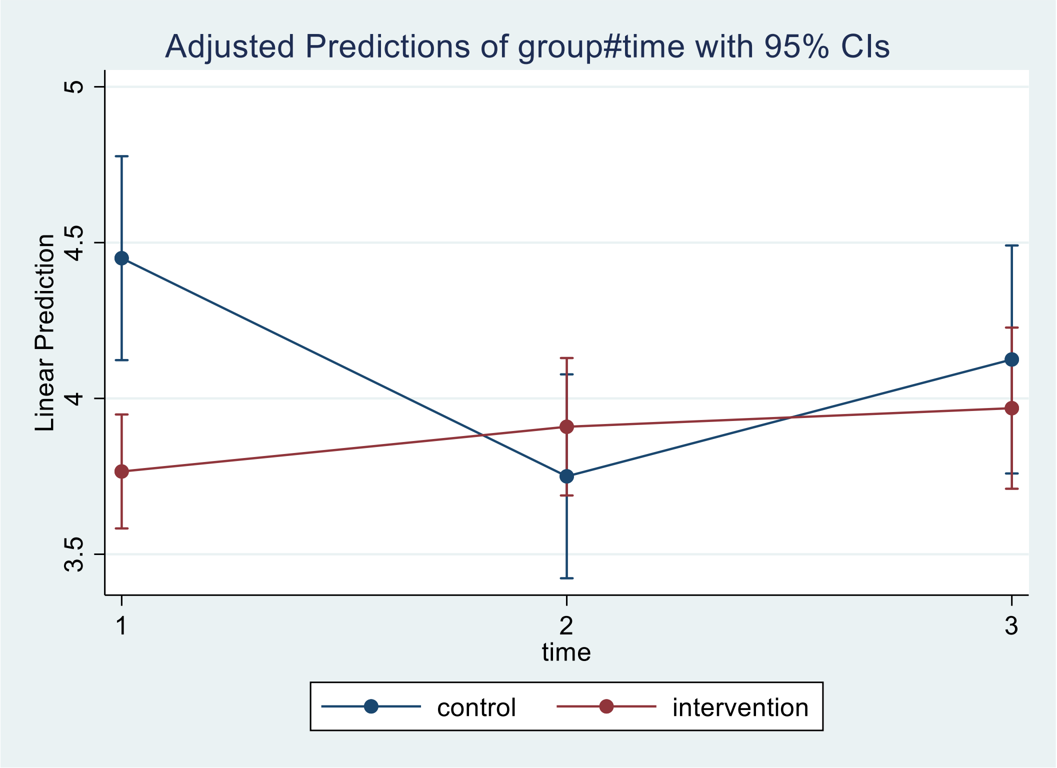
There was no statistically significant difference between the two groups' scores in the group by time interaction ($p = 0.1464$), with no effect size detectable (0.02). There was a small trend in the time interaction ($p = 0.0788$), similarly with no detectable effect size (0.03).

Question 4: The relationship between me and this patient is good.



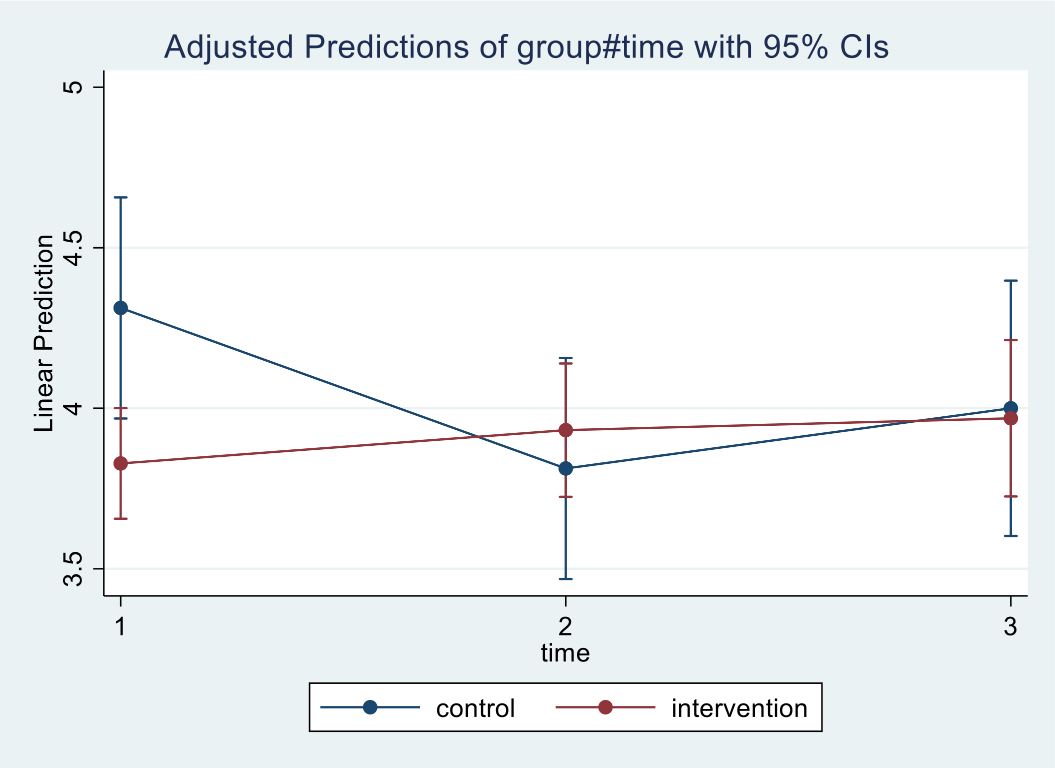
There was a small trend between the two groups' scores in the group by time interaction (*p* = 0.0610), with no effect size detectable (0.03). There was a small trend in the group interaction (*p* = 0.025), similarly with no detectable effect size (0.03).

Question 5: My patient trusts the advice I give them



There was a trend towards statistical significance in the two groups' scores in the group by time interaction (*p* = 0.0094), with no effect size detectable (0.05). There was a small trend in the group interaction (*p* = 0.0580), similarly with no detectable effect size (0.02).

Question 6: My patient trusts the treatment I give them



There was no statistically significant difference between the two groups' scores in the group by time interaction (*p* = 0.0877), with no effect size detectable (0.03), and no other trends or significant differences between the group or time interactions.

Discussion

The above graphs show that there were no significant differences attributed to the group HCPs were in, the time at which they were assessed, or a combination of the two. However, there were small differences in HCPs' ability to communicate with their patients based on which group they were in and for HCUs to communicate with the participating HCPs according to which group they were in. These graphs illustrate that the control group was generally more able to communicate effectively with their patients. Both groups showed an increase in having the resources they needed to communicate, notably with the intervention group showing a larger increase from T1 to T2, and a small, continued increase from T2 to

T3. Aligned with the HCP-HCU communication reflected in Q1 and Q2, the control group also reported higher levels of trust (Q4, Q5 and Q6) at T1 and T3.

c) *Linear mixed models*

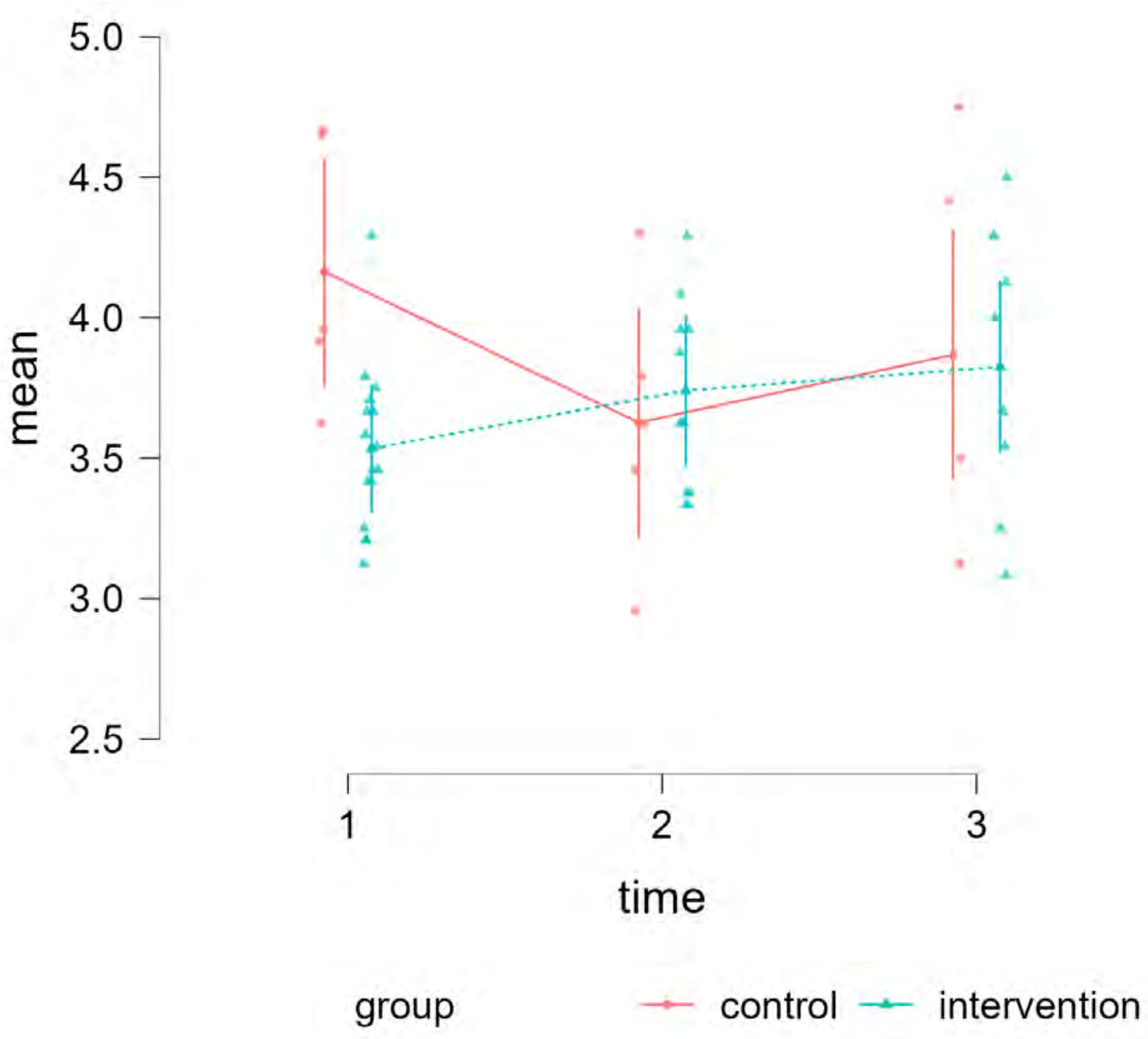
The repeated measures ANOVA was validated using a linear mixed model. One assumption of ANOVA is that all participants are different, and this assumption was violated because each HCP completed four questionnaires (about different HCUs in different consultations) at each time point. Another limitation of the ANOVA is that it only uses data in cases where participants completed questionnaires at all three timepoints, and thus the data was minimised by participant dropout. The linear mixed model considers the dependence of HCU data on the participating HCPs, and it also models data for all timepoints.

ANOVA Summary

Effect	df	ChiSq	p
Intercept	1	92.658	< .001
group	1	1.032	0.310
time	2	1.926	0.382
group ✻ time	2	8.523	0.014

Note. Model terms tested with likelihood ratio tests method.
Note. The following variable is used as a random effects grouping factor: ‘participant’.
Note. Type III Sum of Squares

We tested the intercept of the model. The ChiSq is 92.658 with 1 degree of freedom and it is very significant (*p*<.001). This means that who the HCP is makes a difference to the patient data, illustrating that HCPs experience communication differently and therefore confirming that a communication intervention would affect each HCP differently.



The above plot depicts the estimated marginal means, and the dots and triangles represent the data from each participant. Here we can see that at T3 the intervention and control group overlap, but at T1 the control group scored significantly higher than the intervention group, and the two groups do not overlap.

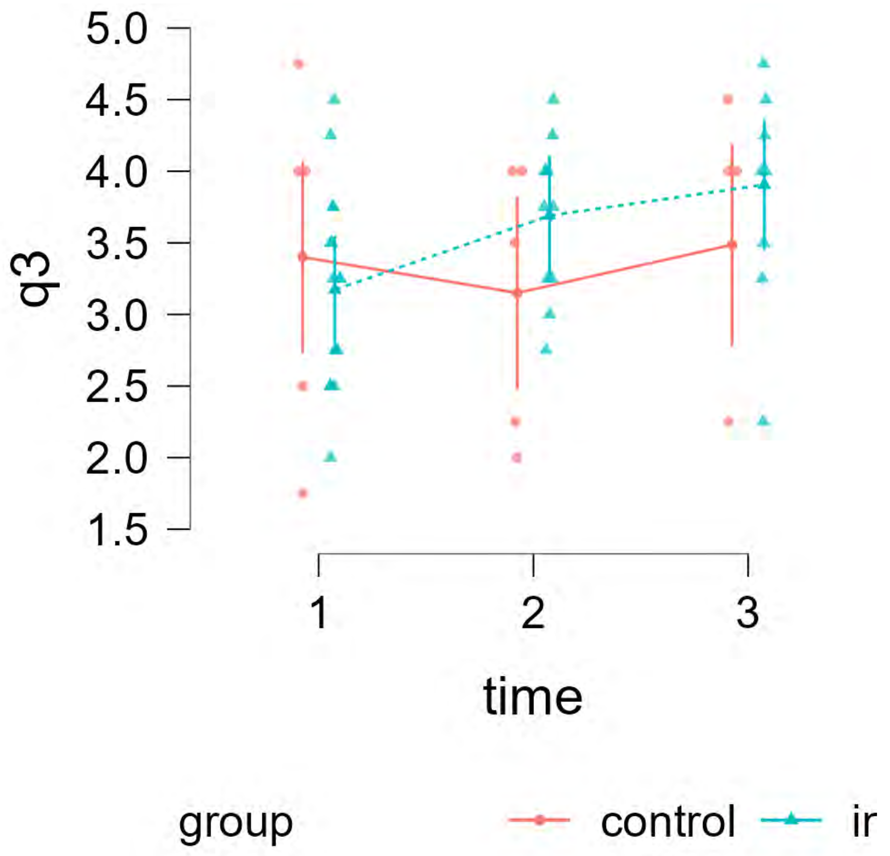
Contrasts

	Estimate	SE	df	z	p†
Contrast 1	-0.629	0.224	∞	-2.805	0.005
Contrast 2	0.207	0.142	∞	1.463	0.144
Contrast 3	0.291	0.159	∞	1.830	0.067

† P-values are not adjusted.

The estimated marginal means were investigated using contrasts, which show the differences between specified groups and timepoints. Contrast 1 represents the difference between the intervention at control group at baseline. Contrasts 2 and 3 represent the change in mean score with the intervention group, with Contrast 2 showing the change from T1 to T2, and Contrast 3 illustrating the change from T1 to T3. These contrasts show that the control group scored higher than the intervention group at baseline, and this confirms that this difference is significant ($p = 0.005$). It also illustrates a trend towards statistical significance in the mean of the scale in the intervention group's increase from T1 to T3 ($p = 0.067$).

Looking at each question individually, the results generally reflected those from the ANOVA, with differences at baseline and some trends towards statistical significance in group and time interactions. The line of best fit generally reflects that of the mean and the estimated marginal means illustrated in ANOVA. Of interest, however, is Q3:



Contrasts were run for Q3:

Contrasts

	Estimate	SE	df	z	p†
Contrast 1	-0.228	0.363	∞	-0.629	0.530
Contrast 2	0.518	0.174	∞	2.971	0.003
Contrast 3	0.734	0.197	∞	3.724	< .001

Contrasts

	Estimate	SE	df	z	p†

† P-values are not adjusted.

There is a significant (p = 0.003) and very significant (p = <.001) effect of time on the intervention group from T1 to T2 and T1 to T3 respectively.

d) Control group

One possible explanation for the unpredictable results of the control group could be the L1s of the HCPs: two of the HCPs in the control group spoke isiXhosa as their L1, while three spoke English or Afrikaans as their L1 (one of whom did not record the languages of the HCUs and therefore this data is not included below). Thus the control group had a larger proportion of isiXhosa L1 HCPs than the intervention group. T1 was the timepoint at which most HCUs shared the L1 of the HCP, for both the English/Afrikaans and isiXhosa group. Therefore it is likely that the high scores at T1 for the control group were due to shared L1s.

```
           |              xhosa (1) or not (0) and l1 of hcu
           |  ─────────────── English/Afrikaans ───────────────────
      time | English/Afrikaans          isiXhosa               Shona
───────────┼───────────────────────────────────────────────────────
         1 |                 5                 3
         2 |                 2                 4
         3 |                 2                 3                 1
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           |              xhosa (1) or not (0) and l1 of hcu
           |  ──────────────────── isiXhosa ───────────────────────
      time | English/Afrikaans          isiXhosa               Shona
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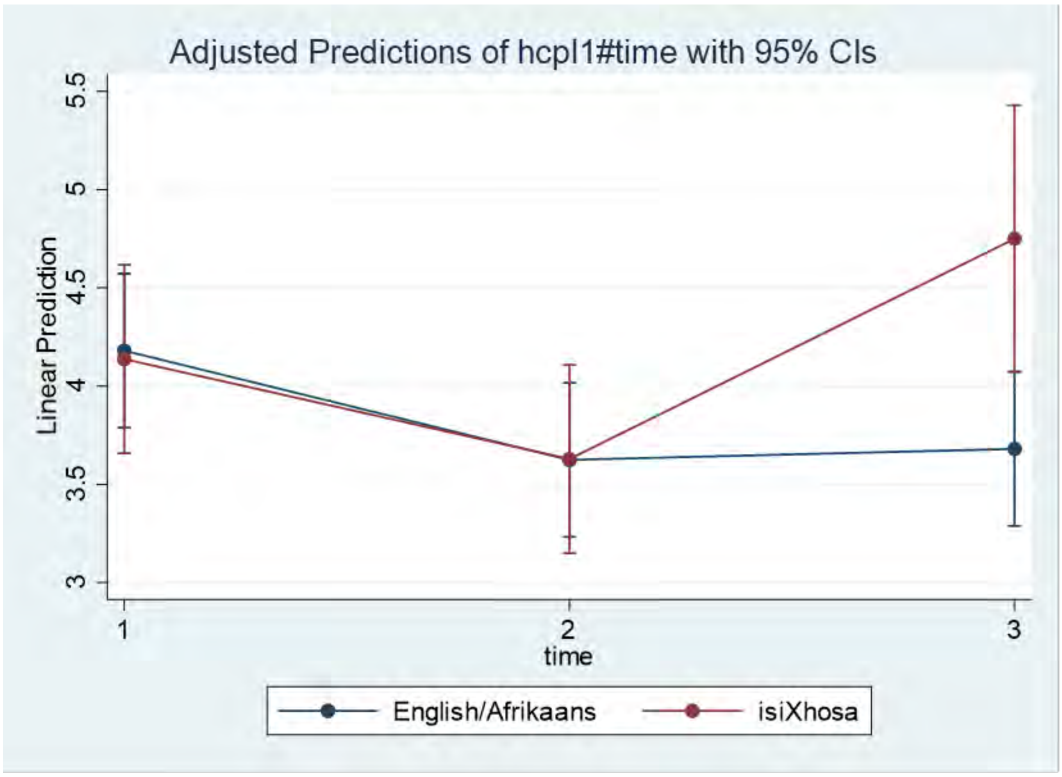


e) Discussion

The pattern of correlations for the control group differed from the intervention group at T1, but were similar at T2 and T3. This suggests that the data collected from the control group at T1 was unusual. The control group consisted of five participants at T1 and T2, and only four at T3. Given the ChiSq and significant intercept of the model, even though there were 16 or 20 questionnaires collected at each time point, that there were only four or five HCPs under which the questionnaires were nested means that even small changes in circumstances or in consultations could make a big difference to the data.

7.4.4. Qualitative data presentation and analysis

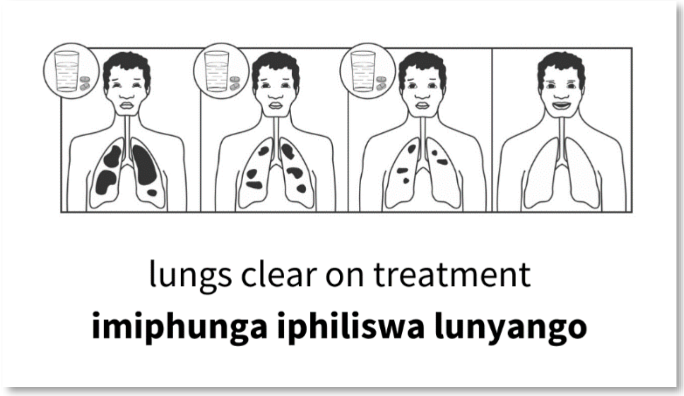
a) Individual unstructured feedback

When explaining the resources at the ARV clinic, the Head of Family Medicine asked why the flashcards were printed that size, and in black and white rather than in colour. It was explained that the flashcards were business-card size so as to easily fit in most people's hands, and based on the feedback we received in the needs analyses where HCPs told us that posters were difficult when working at different sites, and that bigger resources were difficult to keep with them. While explaining this, one of the HCPs present agreed that she could picture herself easily putting the flashcards in her bag and taking them with her to her consultations. One reason for printing in black and white is that health pictograms, such as the USP pictograms, are usually in black and white and so this conforms to health communication norms. Another important reason was the sustainability and replicability of the resources after the intervention: colour printing is often inaccessible or prohibitively expensive, so creating resources that can be printed in black and white allows it to be replicable after the intervention ends. This was explained to the Head of Family Medicine and he agreed with this reasoning.

One participant in particular gave detailed and constructive feedback about how she would like to use the resources. The Doctor of Internal Medicine (former Head of Department) at Mary Malahlela gave feedback on both the printed flashcards and the communication app. She found the app to be most helpful for testing and counselling when a HCU finds out that they are HIV-positive, but does not adequately extend to maintenance and care with chronic patients. She explained in what order she would arrange the flashcards. She noted that having the flashcards and putting them in a specific order could be helpful not only for improving clarity of communication, but also as a prompt for the HCP using them to remind them of what to speak about and in what order.

Some of her suggestions for additions to be made were:

- Adding terms and information about viral load and CD4 count. The literature also indicates that these are terms that often cause or contribute to breakdowns in communication.
- Creating more versions of the 'lungs clear up on treatment' card to include TB of the abdomen and TB of the brain, and to add a card to explain "which TB do you have".



Picture 7: Lungs clear up on treatment flashcard

- A PDF of medication for ARVs, together with a translation of 'Which regimen are you on?"
- Another format she would have found useful would have been a booklet with a few pictograms together on each page, which could then be shared within the ward. In our discussion she considered doing this herself by putting the printed flashcards together and photocopying them into a booklet. Similar to this she suggested having chosen pictograms grouped together onto an A4 sheet that HCUs could take home with them. Both of these suggestions emerge from the possibilities of having printed flashcards that can be arranged and replicated with a photocopy machine. This gives an indication of what modality of resource is appropriate in order for HCPs to be able to adapt them most easily for their own use.

b) Feedback from the WhatsApp group discussion

A WhatsApp feedback group was chosen as the alternative to an in-person focus group discussion due to the popularity and accessibility of WhatsApp in South Africa. It is not only used for informal communication, but also for many types of formal communication, with businesses having business WhatsApp accounts; people can send a WhatsApp voice note to the radio stations; and even an official WhatsApp Help Service for COVID-19 which was then further developed by the World Health Organisation to run a COVID-19 information WhatsApp service (Matiashe 2020). WhatsApp is the most used social media platform in South Africa, and it is used by 93.2% of internet users aged 16 to 64 (Ornico and World Wide Worx, 2021: 62). WhatsApp provides a more affordable alternative to phonecalls, SMSes, and video call services like Skype or Zoom. It was chosen for the focus group discussion and to keep in touch with participants to follow up about questionnaires, or to make appointments to see them, because it was the most efficient way to keep in touch with participants remotely, without participants incurring (notable) data costs for participating. The online and text- or voice-based nature of this feedback group did not show the emotive and interactive elements that would have been evident in a traditional in-person focus group discussion; however, it did gather some group views, and allow for multiple perspectives to be presented and discussed.

After creating the WhatsApp group I sent a voice note and a text message to the group, and encouraged them to reply with a voice note but noted that they could also send a text message if they preferred. Having both as an option had a positive impact: when explaining the study to her colleagues, one HCP noted how easy it would be to participate in the study because it would only involve three questionnaires and a voice note on WhatsApp; however, when the group was running all participants chose to send a text message rather than a voice note.

The feedback given by participants mainly centred around the themes of time, both in terms of the resources taking time to implement, and taking time to get used to; the ease of calling an interpreter relative to using the resources; preference for digital or hardcopy format; and the use of the resources for language learning. The first response received on the group was longer and relatively detailed, which was helpful in that other participants could add their feedback and note what they agreed with about the previous messages.

Several participants noted that using the resource takes time to get used to: "I've never had resources like this to use so getting into the habit of using the cards is a little bit difficult and takes getting used to." (Hayley Greyling, Intern at Lindiwe Sidali Hospital). This reflects Hulman's (2009) explanation that new behavioural skills are consciously acquired, and require "repeated experiences with real world events" (Hulsman, 2009: 305) in order to become scripts that a person uses automatically. Participants were particularly conscious of the extra time needed during times when they were busy, and would then return to their routine ways of practice by calling sometime to interpret: "the busier it gets at work the less likely I am to use them, especially in the setting of a busy clinic with lots of patients waiting I'm more likely to call someone to help translate because it's quicker than trying to use the resources" (Hayley Greyling, Intern at Lindiwe Sidali Hospital). Indeed, time pressure can also impact an HCP's chosen communication (Hulsman, 2009: 306) and would naturally limit the perceived time available to employ new communication behaviours. While some participants prioritised the ease of using an interpreter rather than using the cards (for example, “I do agree with Hayley, it is easier for me to call [a] translator[13]” (Marie du Toit, nurse at Njongwe Support Centre)), most also noted that they believe that using the resources would become easier over time, and expressed their desire to keep trying to use the resources, for example:

- “I would also love more time to use [the resources] / give longer term feedback :)” (Hayley Greyling, Intern at Lindiwe Sidali Hospital)
- “I have found it a bit trickier than expected to have the time to incorporate the tools, but I think that with a bit more practice it will become more streamlined.” (Rose Cheadle, Intern at Lindiwe Sidali Hospital)
- “it is just easier for me to get a translator. But I think with more time I will get more comfortable using them and be able to recognise things easier for use.” (Katelin Fourie, OT at Lindiwe Sidali Hospital)

This can be summarised by the feedback given by James Green, a doctor in the Family Medicine department at Lindiwe Sidali Hospital:

> It still is a little tricky at this stage for me to arrange them the best and unfortunately when the overwhelming feeling of having to “push the queue” descends then one finds that practicing paternalistic medicine returns and one just writes, plans, and hopes that someone explains to them! 🤦🏻‍♂️ [14] I definitely don't like working like that - I feel that the cards, given time and more practice, would really help with breaking down the paternalistic medicine model and hope I can get better at using them! 👍🏻 😊

The preference for calling someone to interpret was not only due to the relative ease, however; in one participant’s case it was also due to the limitations of the resources: “I think in the future it would be very useful to expand on the symptom terms to incorporate more disease specific questions. A lot of the time when I want to ask further important questions regarding the patients symptoms I am unable to and just land up calling a translator.” (Chris Kalloway, Intern at Lindiwe Sidali Hospital).

The potential helpfulness of the resources was also specifically stated by some participants: “It is a great resource though.” (Katelin Fourie, OT at Lindiwe Sidali Hospital) and “I still think they have enormous potential to optimise consultations so definitely want to keep trying

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[13] 'Interpreter' and 'translator' are used interchangeably when including participants' feedback: while interpreter is the more accurate term, translator is also used because of its acceptability in colloquial use.

[14] The quotes have been edited for typos, but emojis have been left in due to their intentional communicative functions (see for example Gawne and McCulloch, 2019).

to incorporate them and then will be able to provide more rigorous feedback 😊” (Rose Cheadle, Intern at Lindiwe Sidali Hospital).

Two participants noted that they had never had a resource like this before, with one noting that the other resources they had seen or used before had always been textbooks or phrasebooks to assist them with isiXhosa.

Two participants noted that they prefer the digital flashcards to the paper flashcards, “because I always have my phone with me” (Hayley Greyling, Intern at Lindiwe Sidali Hospital), and “I tend to forget the cards” (Katelin Fourie, OT at Lindiwe Sidali Hospital).

Two participants explained that they had already been trying to speak isiXhosa in their consultations (“I try my best to speak a bit of isiXhosa with my patients” (James Green, Doctor at Lindiwe Sidali Hospital)) and noted the usefulness of the resources in their efforts: “I found myself using the flashcards to learn the phrase or word in Xhosa. “Off-label use[15]” 🤣” (Robert Krige, Dietician at Mary Malahlela Hospital)

c) *Feedback in follow-up interviews*

When the T3 questionnaires were collected, participants were invited to participate in a one-on-one interview to give their feedback on the resources and on participating in the pilot feasibility trial. The aim of these interviews was to inform the ancillary analysis of the resources, and to continue with a PAR approach to give insights into how to repeat or improve on the feasibility of such an intervention. The specific suggestions made by HCPs to improve the resources are not included here, but were included in Chapter 6 on resource development.

Two participants were selected to participate in these interviews: Chris Kalloway, an Intern who had been working in the outpatient department, casualty department and the wards, and Katelin Fourie, an Occupational Therapist who was doing her Community Service training. Both participants had been recruited at Lindiwe Sidali Hospital (although Kalloway was also

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[15] “Off-label use” refers to the use of a medication in a manner different to that for which it is intended, for example using a medication for a condition it is not approved to treat.

working at Nomusa Shezi Hospital) and spoke English and Afrikaans as their L1s respectively.

i. Difficult points of communication

The words and phrases to be added to the flashcards/flash-glossary included body parts that were difficult to point to or mime, either because they are internal (e.g. lungs, intestine) or because it could be considered inappropriate to point at them (e.g. breasts, penis, vagina).

ii. HCP-HCU relationship

> I think it makes a difference to speak Xhosa. Firstly for the therapeutic relationship, if you greet a patient in the home language it's automatically, I think they feel respected and they see like you do [make] effort as well, but it is just there's a friendliness from both sides. (Katelin Fourie, OT at Lindiwe Sidali Hospital)

The 'helpful phrases' such as 'Are you able to speak English?' play an important role. Even if they do not answer questions from a biomedical perspective, they both contribute towards ethnorelative practice or a biopsychosocial approach, and assist with reducing the existing power dynamics of HCP vs HCU, English speaker[16] vs not able to speak English. This is further described by Kalloway: "Even if you can't have the whole consult [in isiXhosa], I think that if you try [the HCUs] do like it better. I think they feel more comfortable, which help loads."

An interesting point raised by Kalloway was the impact of language barriers on the HCP-HCU relationship because of the frustration felt by the HCP. While the literature presented in this thesis, which broadly reflects the literature on this topic, focuses on HCUs' perspectives and the impacts on treatment, this provided more insight into the HCP's perspective:

> I found that the language barrier is detrimental to both, just like the consultation but [also] the patient's health, as well as like the way I approach the patient. I find that when I can't communicate with the patient properly, I get very frustrated and I'll just go and get a translator. (Chris Kalloway, Intern at Lindiwe Sidali Hospital)

> When I even attempted to speak isiXhosa they [HCUs] appreciated it and sometimes they would laugh a bit – but in a good way – and it would really create a good dynamic and a good patient doctor rapport. When I couldn't speak, then often you're

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[16] This does not assume that the HCP speaks English as their L1, but notes that the HCP is proficient in English, a language which holds prestige that can add to or create power imbalances.

> just like, ‘this is so frustrating’, and a lot of the time you don’t want to come across frustrated. But when you just walk out and get someone, that’s not great, even internally you feel like, ‘I’m upset about this’. (Chris Kalloway, Intern at Lindiwe Sidali Hospital)

iii. Interpreters

Even though (informal) interpreters play a significant role in helping HCPs and HCUs to bridge language barriers, Kalloway would prefer to not need an interpreter: “lots of things are lost in translation, you can’t get your point across, or often I’ll say this whole long thing and then the translator will say, like, two words, and then surely that’s not what I asked.”

iv. Language learning

Both HCPs who participated in the interviews had previously learnt an indigenous South African language, or were taking lessons. Kalloway learnt isiZulu for healthcare in university through the Uthini language programme, which is partnered with WITS University and the Western Cape Education Department. However, now that he is working in the Eastern Cape he needs to use isiXhosa. He explained that he then learnt isiXhosa with Uthini, but because the isiXhosa programme was not medically focused it was less relevant for him. Katelin Fourie, an Occupational Therapist at Lindiwe Sidali Hospital, described the different ways in which she had been learning isiXhosa as follows:

> I started with independent Xhosa classes just because I wanted to communicate better with my patients. It’s 15 minutes every week and it’s basically greeting the patient, reality orientation with them, the pronunciation of all the clicks etcetera – but that is not related to work at all. And then there was an option … if you’d like to learn Xhosa you can do it at the hospital, but we’ve never started with a program …. And then you learn from the patients, and you also learn from the other therapists, like basic words that you need…. (Katelin Fourie, OT at Lindiwe Sidali Hospital)

This affirms that such an intervention is appropriate for HCPs who are already sensitised to communication barriers and are willing to put in their own time to overcome this, and in many cases may already be taking steps to do so. Hulsman’s (2009: 305) assertion that attitudes and self-efficacy are determinants of intention to perform a behaviour, and form a part of behavioural change, is reflected here. It also reflects a common experience of HCPs who would like to learn isiXhosa at their place of work, but have not been granted the opportunity to do so (for example, the HCP at Ncumisa Jilata hospital who had been requesting isiXhosa lessons for the nine years he had been working there). Both Kalloway and Fourie explained that they mostly used the flashcards to refer to themselves, rather than to show to the HCPs, reemphasising their use as language learning devices or glossaries, rather than props or HCU-facing resources.

v. Profession-specific

> I think everyone had a different experience, depending obviously where you are and where you're working: in terms of working in an OPD setting, versus working in a casualty setting, versus a ward; … in terms of how quickly you have to move, what kind of patients you're exposed to; in terms of having translators around, are you forced to sort of push yourself, or is it easier to just ask someone who knows. (Chris Kalloway, Intern at Lindiwe Sidali Hospital)

Kalloway noted how he experienced different time constraints depending on the setting in which he was working (comparing OPD, casualty and the wards), and how this impacted his ability to use the resources. This reflects how communication goals are context-dependent and permanently changing (Hulsman, 2009: 302). In these contexts he was using the symptoms pack of flashcards once or twice a week, and he did not use the TB or medicine flashcards.

While the flashcards were helpful in some situations, in other situations it was still necessary to find someone to interpret, sometimes even after initially using the resources:

> It covered quite a few symptoms, so with quite a few of the patients depending [on] what they presented with you could ask them about that. So that really helped. The problem came in when there weren't the specific symptoms you were looking for, and then when the patient would answer [with] something that you didn't understand, cause if it wasn't just like an *ewe*[17] or *hayi*[18], then you're like, 'I don't understand this, I'm so sorry, I need to get someone'.

Inasmuch as the resources were used differently depending on HCPs' specific professions, they were also used across a variety of conditions:

> I was able to use them across all consults. A lot of patients do have HIV, so it landed up that they did have HIV, but it wasn't strictly to HIV and TB patients it was sort of just everyone. …. A lot of the time also we're working patients up, so you won't know that they have TB until afterwards, and if you're in casualty you won't follow them up so you won't know that they have TB. (Chris Kalloway, Intern at Lindiwe Sidali Hospital)

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[17] "Yes" in isiXhosa.

[18] "No" in isiXhosa.

Taking HCPs' specific professions into account is important not only in terms of the content of the resources, but also in terms of their practicality. As an OT, Fourie noted that she did not use the app because even though she always had her phone with her, it was not convenient to use it when she was with a patient and wearing gloves. Even though both participants suggested more profession-specific words (as detailed in Chapter 6), an advantage of the resources were their specific healthcare focus. As noted by Fourie, "what made it easy to use was that the words were actually there; the relevant terms were there, that you do not always find [in] other places."

vi. Feasibility of the study

The two HCPs interviewed had different experiences of the amount of time between receiving the resources and participating in the WhatsApp feedback group: Kalloway felt that the time was appropriate, while Fourie explained that she had been on a course for a week, and she then did not feel like she had had enough time to practise using the resources before submitting the second questionnaire. With this in mind, Fourie recommended setting the timeline according to HCPs' time with HCUs, rather than a calendar period. This could also be beneficial for other HCPs who explained at different points that they were on sick leave or holiday leave, or were working in a different specialty.

Kalloway described the positive aspects of participating in the WhatsApp feedback group, noting that he appreciated reading the input from other participants: "that initial feedback when everyone was giving their input helped quite a bit, cause you're like 'oh this person has said this, or made this suggestion, ok that I can change, or utilise the material differently'". However, the feedback group could have been improved through more interaction. Kalloway attributed the later lack of interaction to being "person-based", or varying because of the individuals involved; while Fourie noted that an in-person discussion would have been "more interactive and lead to more conversation" as she believed people would feel more accountable if they were having a discussion in person.

Both Kalloway and Fourie agreed that the WhatsApp feedback group could be improved by having an in-person discussion: "an in-person discussion's always nice, it's ideal, instead of one-on-ones or big group online things." (Chris Kalloway). They found that other ways of doing things remotely, and specifically using WhatsApp to send the questionnaires, was doable. Even though this was feasible to collect questionnaires, and could be beneficial for future studies in remote or hard-to-reach locations, individuals' time and other use of WhatsApp should still be kept in mind. Fourie explained why she sometimes sent her questionnaires slightly later than she had intended to: "it's just poor time management I think that made us send it – or me – send it a little bit later. You think, 'ok, I'm not gonna open the message because I want to open it when I can actually do it,' and then it just moves down in your messages and it gets lost in between them." Fourie also pointed out that even though it was feasible to send the questionnaires by WhatsApp, participants may have felt a greater sense of accountability if there had been more in-person contact.

Overall, both participants believed in the aims of the study, and were glad to have participated:

> I really I did enjoy [participating in the study], it was useful. I think it has great potential. It makes a huge difference being able to speak the patient's language, it really does, so ya, the ideal is to be able to communicate ourselves with the patients, so I look forward to the expansion.

7.4.5. Discussion

The difference in human resources across different sites impacted the need for and use of communication resources. While the Nurse at Njongwe Support Centre found it was easier to call someone to interpret for her, the Dietician at Mary Malahlela found that calling someone to interpret could take up to 20 minutes and therefore he would prefer to use resources, if possible. There were therefore rather different opinions about having assistance from interpreters: much reflected the literature that describes HCPs' frustration with interpreters, especially their concern that not everything is being translated. The literature draws attention to interpreters increasing the length of a consultation because of the actual interpreting, but a common theme in the feedback from HCPs was that the biggest time consideration with having someone interpret was the time taken to find someone to interpret. On the other hand, some HCPs had integrated working with interpreters in their practice.

"Off-label use": several HCPs used the resources to improve their isiXhosa proficiency; particularly those who mentioned already trying to speak isiXhosa in their consultations. This illustrates the importance of self-efficacy and a sensitivity to language barriers. It also illustrates the usefulness of a field trial, where resources are tried in real settings to see what works best and what is most needed and feasible.

The insights from the feedback interviews could also explain why using the resources for language learning was so common with the participating HCPs: isiXhosa lessons were not readily available for HCPs at the sites where they work, yet several HCPs were already taking independent steps to learn isiXhosa. Since they had already begun learning independently, it could be more natural for them to build what resources they received into their existing efforts.

This also points to the importance of language learning. My own preconception before beginning these studies was that language learning was too big a task to undertake or offer in what was supposed to be a "short and easy" intervention. When learning a language, it takes three to five years to gain basic interpersonal communication skills, and four to seven years to attain cognitive academic language proficiency (Hakuta et al. in Valdés, 2004: 10), with full healthcare communication requiring some of both types of proficiencies. I had expected language learning to be beyond the scope of this study, and the idea of including language learning seemed in juxtaposition to easy-to-implement resources that could be learnt during a 10-week intervention. The feedback from the participating HCPs illustrates that the contrary is true: in undertaking a medical degree, HCPs have already made a long-term commitment; and in many cases my impression was that the participating HCPs were willing – if not eager – to make another long-term commitment to learning the language that would enable them to communicate better with their HCUs.

The suspected limitation of the resources was confirmed by the HCPs' feedback, particularly the feedback given by Kalloway. While the resources were helpful for HCPs to communicate with HCUs, they were very limited in facilitating communication from HCUs to HCPs. In order to truly foster a biopsychosocial approach, future resources packs should aim to include resources that facilitate this.

The use of WhatsApp for conducting fieldwork remotely has important implications not only for during a pandemic, but also for conducting research in remote or hard-to-reach locations. While the – unsurprising – overall finding is that in-person fieldwork produces better interactions and better results, the use of WhatsApp to have a group discussion and to collect questionnaires gives insights into how this could be used when a site cannot be easily reached, or when funding is limited. While it is clear that an in-person feedback group is preferred, if an online group such as the WhatsApp feedback group is conducted again, it could be improved through the researcher or facilitator taking a more active role to encourage interaction, and questions could be introduced over time with asynchronous responses.

These findings also show that in order to target a specific disease(s), such a health communication intervention would benefit from having an integrated approach.

7.5. Recommendations

Drawing on the implementation of the pilot feasibility trial and its findings, the following five recommendations should be considered for a future trial. Firstly, the communication resources should be tailored further in order to be more specific to each profession. From the observations of sites participating in this study, Allied Health at many of the sites had many HCPs who are not isiXhosa L1 speakers, yet this is a field of healthcare that has received relatively little attention in the literature on health communication.

Secondly, it is clear from the needs analyses and the pilot feasibility trial that HCPs' existing sensitivity to communication issues is an influencing factor on whether or not they choose to use health communication resources or participate in a study such as this one. In the visits to the sites and the first meetings with participants it was evident that the first meeting was not sufficient to sensitise potential participants to communication issues when also explaining the study. It is recommended that HCPs-in-training are sensitised to these issues during their university courses, both in terms of learning the local language and exploring options to navigate communication barriers, but also to understand the importance of language and communication from a biopsychosocial medical perspective.

Thirdly, research similar to this would benefit from following a PAR methodology more closely. While this research drew from this methodology, it was adapted and detached from PAR for various reasons, due in part to my own position from outside the healthcare field, and largely due to the impact of Covid. The collaboration with HCPs like the Doctor of Internal Medicine at Mary Malahlela Hospital and the team at Ncumisa Jilata Hospital provides a preview for what PAR could look like in such a study. Working in this way builds rapport and trust, and the teams' first-hand knowledge of what is and is not possible or helpful for them helps to shape the research in the most feasible way possible. These participants' interest in the issue of health communication and in the research design, and their ability to recruit other members of staff, were of great benefit to the development of this study. The increased support for PAR methodologies by universities will also make a significant difference in the practicalities of conducting research such as this, for example the course on PAR developed by the Rhodes University Community Engagement Department, together with the reworked ethical clearance process.

Conducting this research remotely was a response to the pandemic conditions. Fourthly, while some elements of remote research could be included in a future trial, certain parts should be done in person where possible, or arranged slightly differently. Collecting questionnaires from the participants remotely was manageable, especially because most participants completed their first questionnaire in the presence of myself and my research assistant. However, if there was any extra data that needed to be collected, even if it was small amounts of information (for example information about HCPs' or HCUs' home languages), this proved to be difficult. Future trials would benefit from collecting as much once-off data as possible at the first in-person visit, conducting the first round of data collection in person, and following up remotely for the repeated measures. As indicated in the interview data, the research would have benefitted from having the focus group discussion in person, in order to facilitate more in-depth discussion, and to add a sense of accountability and motivation for participants both to participate in the focus group discussion and to continue to participate in the research.

Finally, this intervention, or something similar, could be further developed into a short communication course to be included as part of CME at teaching hospitals. For example, I was invited to introduce the research (briefly) at the Family Medicine weekly meeting at Lindiwe Sidali Hospital, which I introduced after a one-hour presentation on prescribing medication for asthma. As hospitals such as these are committed to CME, it should be feasible to have one one-hour session to sensitise HCPs to communication issues and do some preliminary training, and another follow-up session after about six weeks (noting that, as discussed in the WhatsApp group, one month was not long enough for many HCPs).

7.6. Conclusion

This chapter has described the pilot feasibility trial in detail. The aims of the intervention have been presented in relation to the overarching research questions of this research, namely research questions 2, 3 and 4: *What communication resources and training are appropriate for the provision of HIV/AIDS and TB healthcare in South Africa? How feasible is it to measure the suggested resources and training?* and *What are the effects of the suggested communication resources and training in healthcare provision?*The intervention has been described in terms of the feasibility of setting up the trial, by outlining the resources and training manual received by the intervention group, and the manner in which data was collected, detailing the use of WhatsApp for data collection. The sites and participants have been detailed, together with the sampling criteria and participant flow. The impact of COVID-19 on the feasibility, set-up and participant retention has also been noted. The feasibility of the trial has been explored, considering the ethics of the trial, conducting the trial online, and the acceptability of the intervention. It was found that different recruitment methods worked better at different sites, depending on the systems already in place at the site; that HCPs' interest in the study depended on their profession and in particular on their existing sensitivity to healthcare communication issues; and that the PAR methodology allowed for participating HCPs to play an important role in the development and implementation of the study. The feasibility of the resources was considered as an ancillary analysis, where a small (not statistically significant) upward trend was seen in the intervention group from T1 to T3 in their self-reporting of communication and trust between them and the HCUs they consulted. The qualitative feedback from HCPs gave insights into HCPs' individual contexts and preferences, revealing a general preference for resources that facilitated language learning and HCPs' agency in using the resources in the ways they found most appropriate and useful.

As a full-scale trial, this would not be feasible as it currently stands. Changes should be made such as tailoring the communication resources specific to each profession, sensitising potential HCP participants to issues of healthcare communication, carefully planning and closely following a PAR methodology, and conducting the research – particularly the initial steps – in person where possible. In order for the resources to be appropriate for HIV/AIDS and TB, they need to be useful holistically or from a systems approach. While a pamphlet, poster or video has specific information that could have a single focus, resources that aim to become part of communication in a healthcare consultation need to be broader. Of course, it is important to still have information specific to HIV/AIDS and/or TB, or indeed whichever disease the HCU is being treated for. However, for HCPs to be able to use the resources consistently, and in order to use them with HCUs who are living with HIV/AIDS and/or TB but not necessarily being treated for that disease specifically, they need to be broader.

Chapter 2 of this thesis presented literature that illustrates the prevalence and impact of communication barriers in healthcare in South Africa. This includes communication specific to the healthcare setting, where terminology and jargon can cause or further contribute to communication barriers, either across or within shared languages. The needs analyses presented in Chapter 5 provided evidence of the need for communication resources, and the potential feasibility of a healthcare communication intervention. An overview of the existing healthcare communication resources and training available was given in Chapter 6. The commonplace reliance on interpreters to bridge language (and cultural) barriers in the healthcare setting has been shown to sometimes improve communication on the one hand, but can also have a negative impact on the relationship between the HCP and the person interpreting, with interpreting often not being perceived as accurate or sufficient and with HCPs in the needs analysis reporting that communication was not greatly improved by having an interpreter present. The feedback from HCPs in the pilot feasibility trial showed the notable impact finding an interpreter can have on time in a consultation, sometimes taking 20 minutes to find someone to interpret. The *Healthy Talk* intervention was created in an effort to bridge communication barriers, and minimise the reliance on healthcare terminology and the need to have an interpreter when language barriers are present and an interpreter is not available. This intervention, as implemented as part of a pilot feasibility trial, has been detailed in this chapter. Considered as a whole, it is clear that greater support is needed for HCPs to communicate better across language barriers with HCUs, and this pilot feasibility trial has provided an option to build upon in order to do this.

Chapter 8: General discussion and conclusions

8.1. Summary of main findings

Many HCUs in South Africa are systematically disadvantaged through HCPs' inability to communicate with them effectively. Only a minority of HCPs (with the exception of nurses) are able to conduct healthcare consultations in the L1 of the HCU, which means that HCUs cannot rely on HCPs to help them understand their condition, or to fully involve them in decisions about their health.

This research has explored how HCPs communicate with HCUs when they are not fluent in the same language, ranging from assistance from an interpreter, to using the language of the HCU, to consciously or subconsciously ignoring communication barriers.

This study set out to address the problem of health communication in South Africa through a participatory action research approach. Two needs analysis studies were conducted, which reflected HCPs' difficulties in communicating with HCUs, and which suggested that resources should be made available to assist HCPs to communicate with HCUs. While there are already some health communication resources available in South Africa, access to these is either limited, or they are not widely known or commonly used. This research confirms that there is no one-size-fits-all solution for resources and training to improve HCP-HCU communication. However, some insights were made into what HCPs would like, and what is most feasible in practice. Through the PAR approach it was found that in order to address the communication barriers that HCPs were encountering in their HIV/AIDS and TB consultations, a broader communication intervention was necessary– both for the feasibility of the trial, and for its utility and relevance for HCPs.

The resources of pictogram flashcards and a health communication app were selected to try out with participating HCPs. After one month of using the resources a small (not statistically significant) improvement was seen in HCPs' self-reported communication in consultations with HCUs, with the most notable improvement being in HCPs' self-reported access to the resources they need to communicate effectively in their consultations. This trend continued, to a lesser extent, at the final measurement moment one month after that. The qualitative data suggests that the most appropriate resources are those that HCPs can use in the ways that suit them best, and therefore that are flexible (not necessarily ready-made). While HCPs who are already sensitised to communication barriers are likely to invest time into trying out resources, even when they are not as easy to implement as expected, resources that are easy to implement are likely to have the greatest uptake in busy settings when HCPs do not have time to invest in trying out new resources in their consultations. Since HCPs who are already sensitised to communication barriers have often taken their own steps to learn the local language, resources that support HCPs' language learning are particularly appropriate.

Through a pilot feasibility trial it was found that a full-scale RCT could be feasible if certain steps are taken, particularly if a larger number of healthcare sites are included, and initial visits, training and follow-up training are done in-person (rather than online). An RCT would benefit from a participatory approach similar to that used for the pilot feasibility trial, to ensure that the resources and the study itself align with the needs of those involved, and such that the study is strengthened by the expertise of those participating.

Communication gaps, particularly those caused by language barriers, continue to affect HCPs and HCUs, and this research has found that HCPs do not have the support they need at a structural level. While this study found that many HCPs were already taking steps to improve their language proficiencies, they simply did not have the resources or training they needed in order to shift from a reliance on interpreters or non-engaged communication towards a more patient-centred model of care.

The tendency for participating HCPs towards using the resources for language learning could be understood either as a broad desire for language learning, or conversely as a notable indicator for which HCPs chose to participate in the research. i.e. those who were already sensitive to language barriers and wished to change them could be the same people who (a) would want to participate in this research and (b) would have already been interested in learning isiXhosa.

8.2. Implications

This research has implications at the university, healthcare site, and healthcare policy levels.

South African universities have already taken commendable steps to include communication as part of healthcare degrees through the language courses included. These are of particular importance to sensitise HCPs-in-training to the importance of communication. However, one year of a language course cannot prepare one to then use a language fluently in clinical practice, and oftentimes HCPs end up working in a different province or language community to where they studied. Therefore, HCPs-in-training should be equipped with strategies and resources that they can use themselves, that can be adapted to whichever language community they may work in.

As it was found in this study that many HCPs were already taking steps to improve their isiXhosa proficiency, HCPs' desire for language learning support at the workplace is not a new finding (see for example Crawford, 1999); however, it was interesting to see what this desire looks like when HCPs were presented with other opportunities to improve their communication. If HCUs are to receive quality healthcare, HCPs should be given more support in learning the local language. This research has provided some insight into what this could look like from an independent, self-study perspective. Such an intervention could be feasible, cost-effective and (based on individual HCPs' pre-existing commitment to language learning) could be sustainable, and for these reasons such resources and training should be pursued further. Teaching hospitals and all healthcare sites that include CME could incorporate communications training. Teaching hospitals can use time allocated to CME to give training on health communication – while language classes require regular lessons, many HCPs who are already sensitised to health communication issues are taking on extra work themselves, and including two sessions on health communication tools would better equip them for the work they are doing of their own accord.

National policies are already in place to support healthcare provision in the language of the HCU, and policies at the healthcare site level were beyond the scope of this research; therefore, no specific recommendations for policy creation are made here. However, I do recommend that the insights gained by this research, particularly in terms of how to support HCPs bridge communication barriers, are followed to support these existing policies.

While the health communication resources and training presented in this thesis are intended to have the potential for use in routine healthcare practice, I wish to emphasise that these types of resources and training should not be a panacea for language barriers. It is imperative that the burden of communication is alleviated from HCUs, and that HCPs receive support in learning the local language of the communities in which they work.

8.3. Limitations

The most notable limitations of this study were the exclusion of HCUs and the small sample size of participating HCPs. While it was not possible to include HCUs due to the various impacts of the pandemic, the absence of HCUs in this research is the biggest limitation. While this research strives to effect HCPs' communication, the ways in which this communication could be effected were determined only by HCPs, despite the aim of this research to improve healthcare received by HCUs.

The second notable limitation of this research is the small sample size. The reasons for this (largely pandemic-related, as well as related to ethical clearance and gatekeepers' permissions) were detailed in Chapter 5 and Chapter 7, but the overall limitation of this should be kept in mind whenever the findings of this research are considered.

8.4. Recommendations for further research

These results give theoretical and empirical support for the following recommendations:

1. Employ an in-person or blended approach

Do things in person rather than online where possible. A blended approach is fine, but the in-person element makes a significant difference. I strongly recommend that – at a minimum – the introductory meeting is done in person. Thereafter, if necessary, it could be possible to collect questionnaires remotely, or even to conduct a feedback discussion remotely *if* the other recommendations on this are followed too. This suggestion (in-person meeting with WhatsApp follow-ups) could have a significant impact on more inclusive research, where sites that are usually not considered due to accessibility could be considered.

2. Build awareness of the role of communication

As is seen in the literature and reflected by the different opinions of HCPs in the needs analyses, some HCPs take responsibility for the communication in their consultations, while others either are not aware of it, or place the responsibility on the language proficiencies and/or health literacy of the HCU. The target group of this research was HCPs who were already interested in communication, and therefore efforts to sensitise HCPs to the role of communication in healthcare were not made beyond a short summary or discussion when introducing the research. However, in order for an RCT to be conducted, and indeed in order for more HCPs to take measures to improve their communication, it is important that HCPs are aware of the role of communication in patient-centred, biopsychosocial models of care. By incorporating an awareness of this into the training, as well as into the research pitch (for example when seeking permission or support from CEOs or Managers), more HCPs could be reached, and greater value may be seen in the study and indeed in communication.

3. Reflect participants' agency through flexible resources

When I began this research, it was with the intention to implement something that was easy to implement and would take minimal time investment from HCPs. It was also intended to aim the study at those HCPs who were already sensitised to communication issues and wanted to do something about it. In the course of this research it became apparent to me that I had somewhat underestimated the commitment of participating HCPs and the amount of time and effort they were willing to put into improving communication between them and their HCUs. As became evident through the qualitative data from the pilot feasibility trial, many HCPs used (or planned to use) the resources in ways other than what was intended, according to their pre-existing communication strategies or according to how they believed they could fill the biggest communication gaps. With this in mind, I strongly recommend that health communication resources be not only easy to learn to use, but can be used or adapted over time according to the needs and preferences of HCPs.

8.5. Summary

In sum, this research has shown the unsurprising finding that there are no easy fixes to the language and communication barriers in South African healthcare. However, it has laid a stable groundwork on which to build training and resources to assist HCPs improve communication across these language barriers. This study has used empirical evidence to give further detail to problems of health communication in a multilingual South Africa – as is already well-established in the literature. It has used this to build theories on how health communication could be improved, and has taken practical steps to test this. If this is taken further, the implications could be a more just society with a holistic approach to healthcare, where access to healthcare includes the agency and self-determination that comes with understanding one's health and being involved in decision-making.

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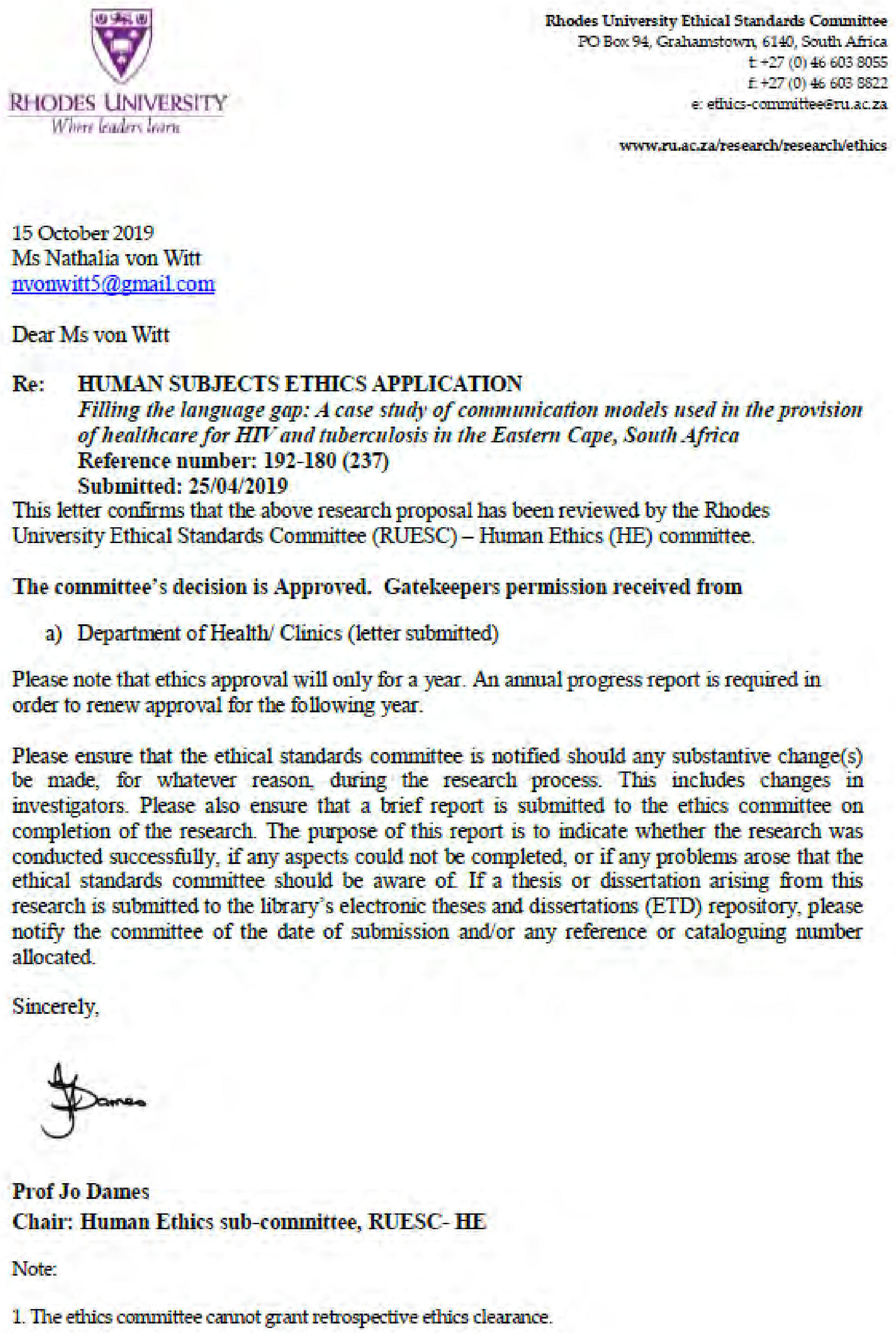
Appendices

Permission letters

Note: Permission letters from individual sites are not included here, in order to preserve anonymity.

Appendix 1: Permission letter from Rhodes University Ethical Standards Committee



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Rhodes University Ethical Standards Committee
PO Box 94, Grahamstown, 6140, South Africa
t: +27 (0) 46 603 8055
f: +27 (0) 46 603 8822
e: ethics-committee@ru.ac.za

www.ru.ac.za/research/research/ethics

15 October 2019
Ms Nathalia von Witt
nvonwitt5@gmail.com

Dear Ms von Witt

Re: HUMAN SUBJECTS ETHICS APPLICATION
Filling the language gap: A case study of communication models used in the provision of healthcare for HIV and tuberculosis in the Eastern Cape, South Africa
Reference number: 192-180 (237)
Submitted: 25/04/2019

This letter confirms that the above research proposal has been reviewed by the Rhodes University Ethical Standards Committee (RUESC) – Human Ethics (HE) committee.

The committee's decision is Approved. Gatekeepers permission received from

a) Department of Health/ Clinics (letter submitted)

Please note that ethics approval will only for a year. An annual progress report is required in order to renew approval for the following year.

Please ensure that the ethical standards committee is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators. Please also ensure that a brief report is submitted to the ethics committee on completion of the research. The purpose of this report is to indicate whether the research was conducted successfully, if any aspects could not be completed, or if any problems arose that the ethical standards committee should be aware of. If a thesis or dissertation arising from this research is submitted to the library's electronic theses and dissertations (ETD) repository, please notify the committee of the date of submission and/or any reference or cataloguing number allocated.

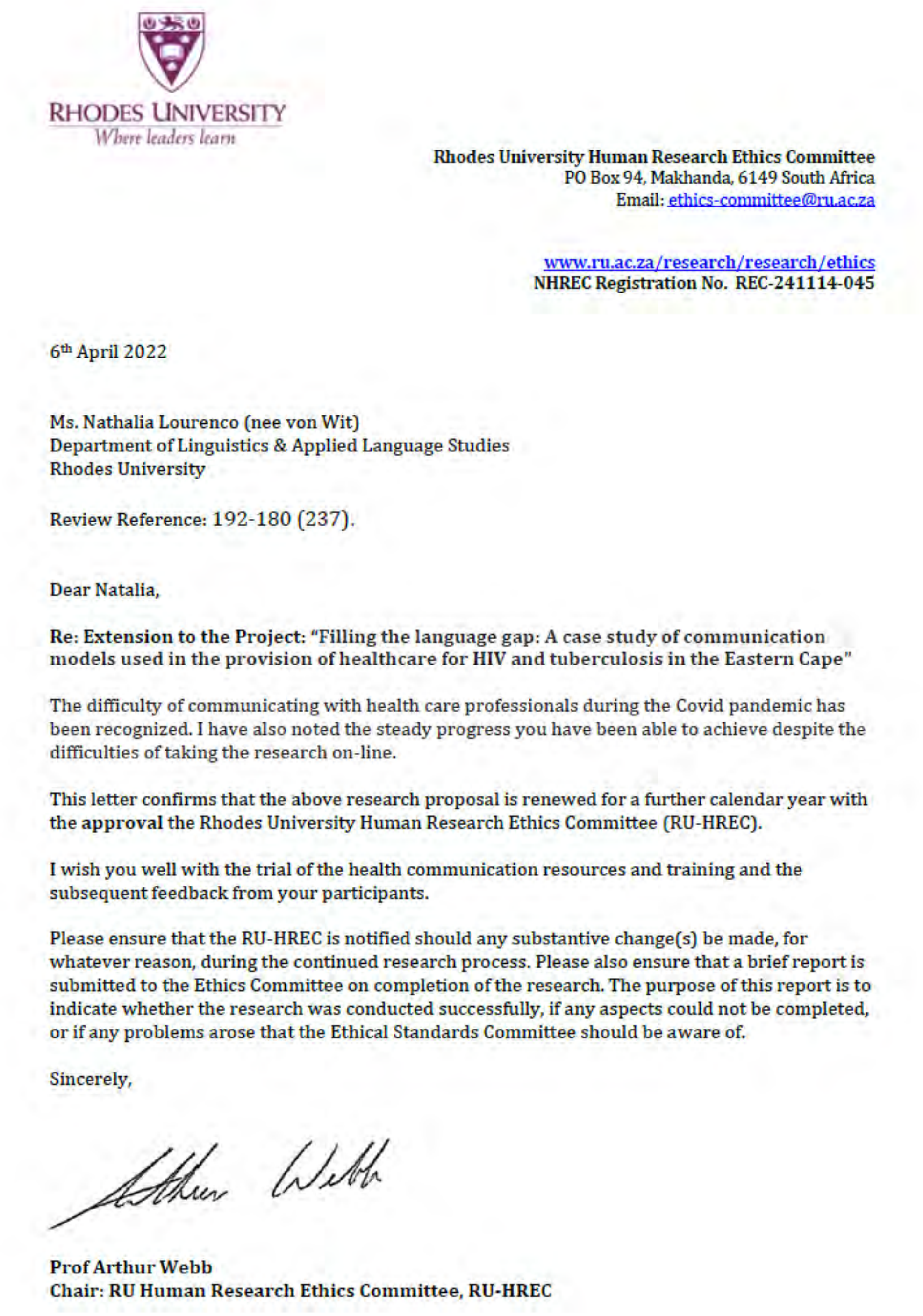
Sincerely,

Prof Jo Dames
Chair: Human Ethics sub-committee, RUESC- HE

Note:

1. The ethics committee cannot grant retrospective ethics clearance.

Appendix 2: Rhodes University ethical clearance: Revised for COVID-19



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Rhodes University Human Research Ethics Committee
PO Box 94, Makhanda, 6149 South Africa
Email: ethics-committee@ru.ac.za

www.ru.ac.za/research/research/ethics
NHREC Registration No. REC-241114-045

6th April 2022

Ms. Nathalia Lourenco (nee von Wit)
Department of Linguistics & Applied Language Studies
Rhodes University

Review Reference: 192-180 (237).

Dear Natalia,

Re: Extension to the Project: "Filling the language gap: A case study of communication models used in the provision of healthcare for HIV and tuberculosis in the Eastern Cape"

The difficulty of communicating with health care professionals during the Covid pandemic has been recognized. I have also noted the steady progress you have been able to achieve despite the difficulties of taking the research on-line.

This letter confirms that the above research proposal is renewed for a further calendar year with the **approval** the Rhodes University Human Research Ethics Committee (RU-HREC).

I wish you well with the trial of the health communication resources and training and the subsequent feedback from your participants.

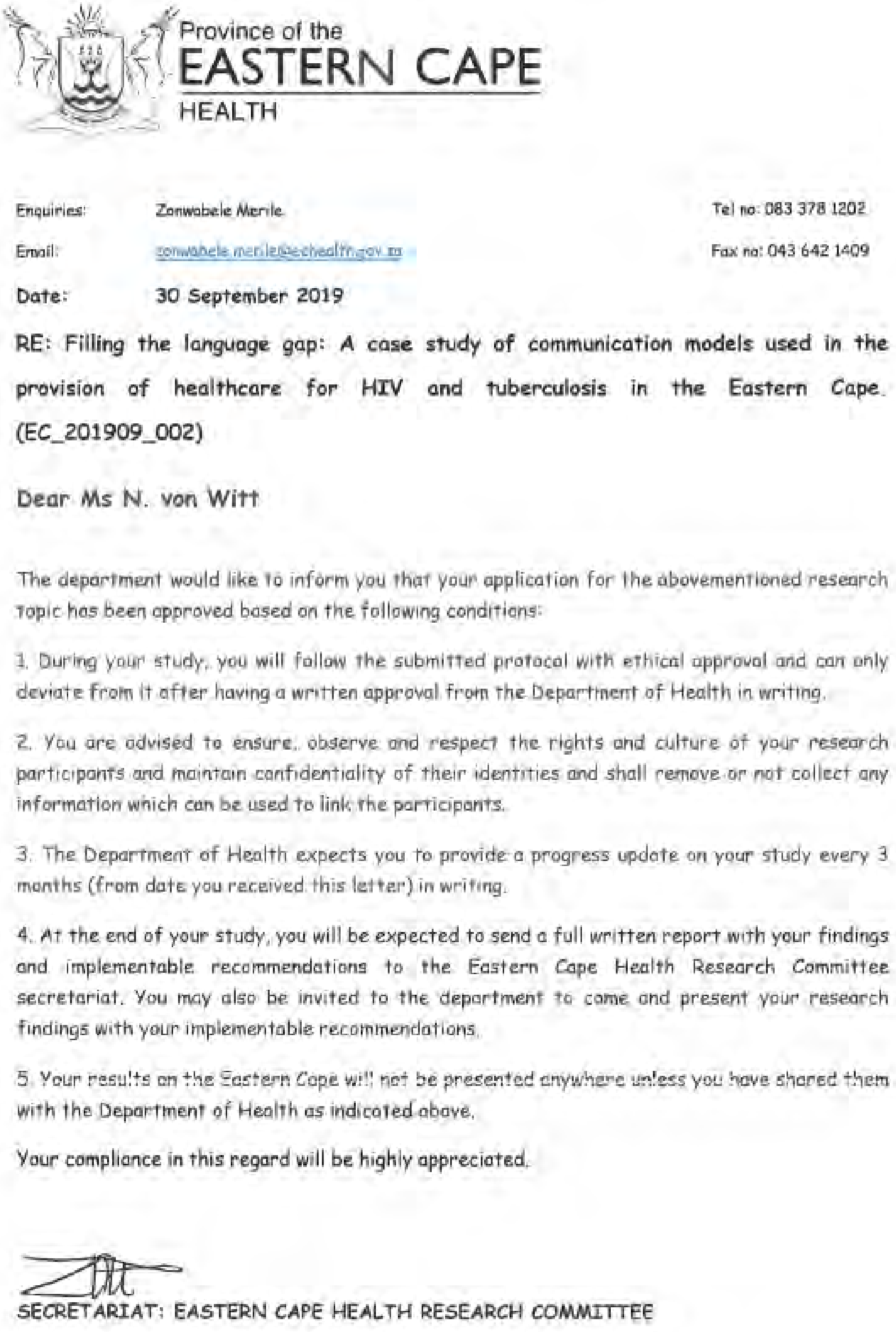
Please ensure that the RU-HREC is notified should any substantive change(s) be made, for whatever reason, during the continued research process. Please also ensure that a brief report is submitted to the Ethics Committee on completion of the research. The purpose of this report is to indicate whether the research was conducted successfully, if any aspects could not be completed, or if any problems arose that the Ethical Standards Committee should be aware of.

Sincerely,

Arthur Webb

Prof Arthur Webb
Chair: RU Human Research Ethics Committee, RU-HREC

Appendix 3: Eastern Cape Department of Health ethical clearance



Province of the
EASTERN CAPE
HEALTH

Enquiries: Zonwabele Merile Tel no: 083 378 1202
Email: zonwabele.merile@echealth.gov.za Fax no: 043 642 1409

Date: **30 September 2019**

RE: Filling the language gap: A case study of communication models used in the provision of healthcare for HIV and tuberculosis in the Eastern Cape. (EC_201909_002)

Dear Ms N. von Witt

The department would like to inform you that your application for the abovementioned research topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.

2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.

3. The Department of Health expects you to provide a progress update on your study every 3 months (from date you received this letter) in writing.

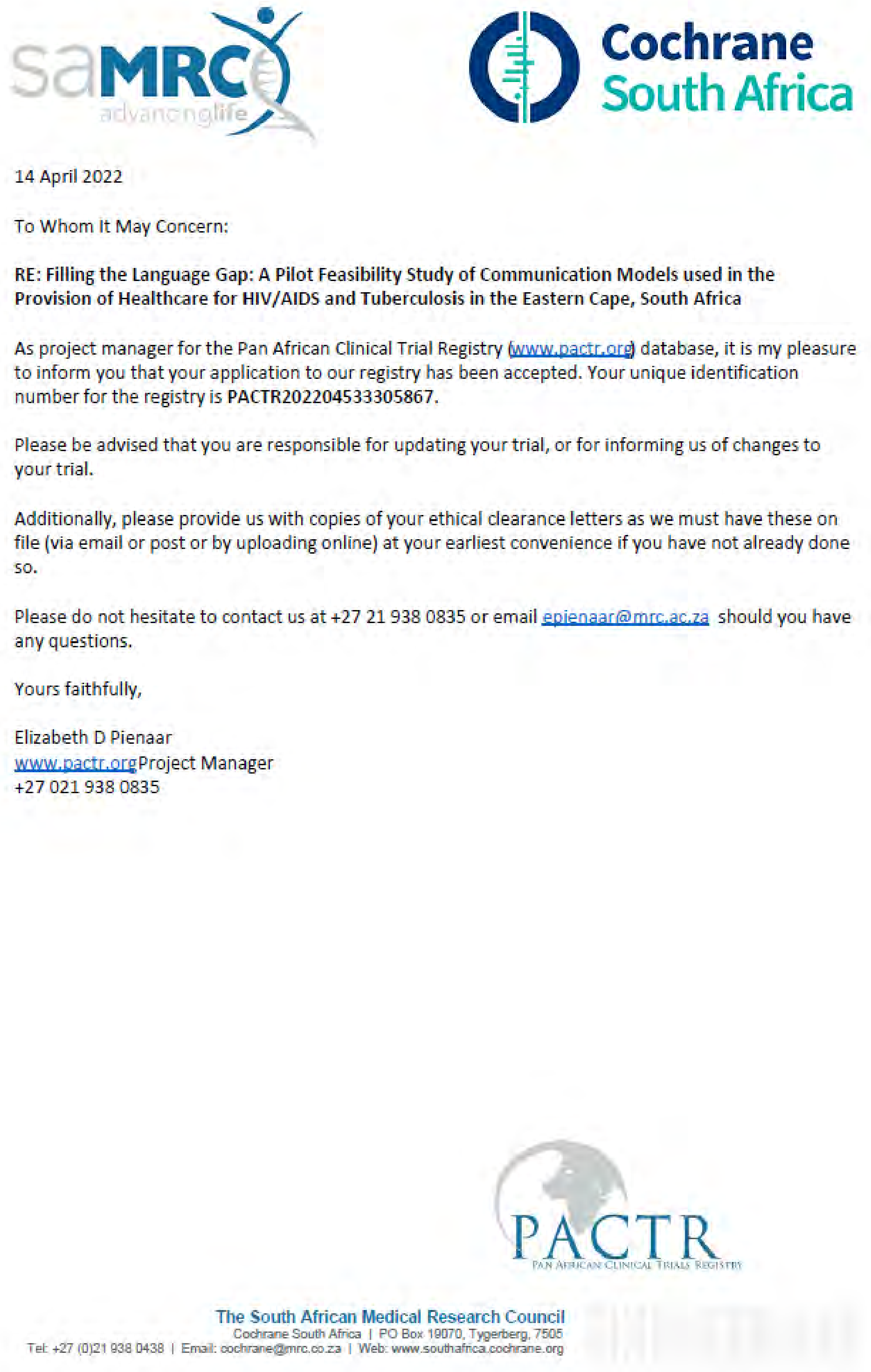
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Eastern Cape Health Research Committee secretariat. You may also be invited to the department to come and present your research findings with your implementable recommendations.

5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

SECRETARIAT: EASTERN CAPE HEALTH RESEARCH COMMITTEE

Appendix 4: Trial registration



14 April 2022

To Whom It May Concern:

RE: Filling the Language Gap: A Pilot Feasibility Study of Communication Models used in the Provision of Healthcare for HIV/AIDS and Tuberculosis in the Eastern Cape, South Africa

As project manager for the Pan African Clinical Trial Registry (www.pactr.org) database, it is my pleasure to inform you that your application to our registry has been accepted. Your unique identification number for the registry is **PACTR202204533305867.**

Please be advised that you are responsible for updating your trial, or for informing us of changes to your trial.

Additionally, please provide us with copies of your ethical clearance letters as we must have these on file (via email or post or by uploading online) at your earliest convenience if you have not already done so.

Please do not hesitate to contact us at +27 21 938 0835 or email epienaar@mrc.ac.za should you have any questions.

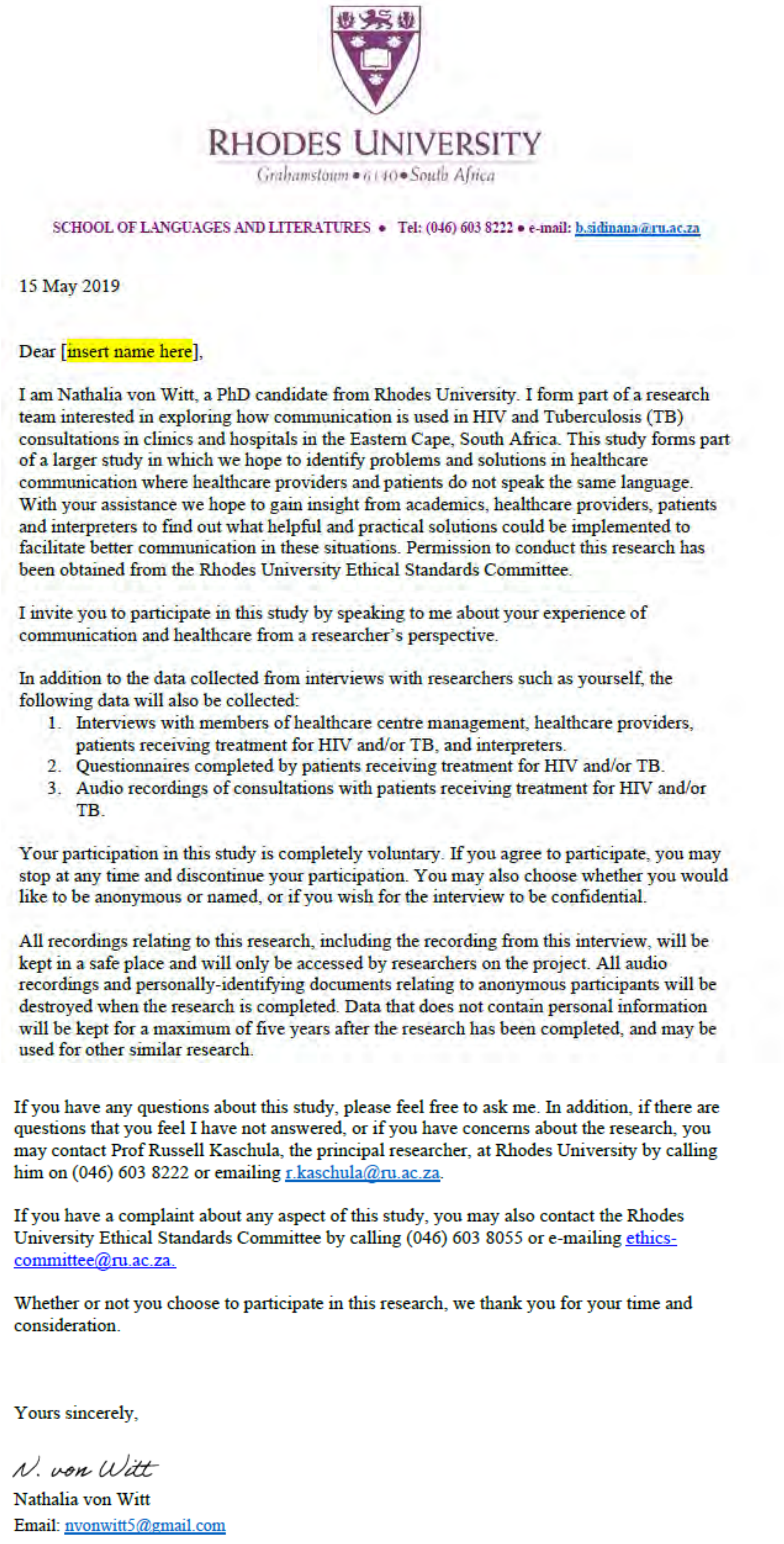
Yours faithfully,

Elizabeth D Pienaar
www.pactr.orgProject Manager
+27 021 938 0835

The South African Medical Research Council
Cochrane South Africa | PO Box 19070, Tygerberg, 7505
Tel: +27 (0)21 938 0438 | Email: cochrane@mrc.co.za | Web: www.southafrica.cochrane.org

Information sheets and consent forms

Appendix 5: Information sheet and consent form for interviews with health communication experts



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Grahamstown • 6140 • South Africa

SCHOOL OF LANGUAGES AND LITERATURES • Tel: (046) 603 8222 • e-mail: b.sidinana@ru.ac.za

15 May 2019

Dear [insert name here],

I am Nathalia von Witt, a PhD candidate from Rhodes University. I form part of a research team interested in exploring how communication is used in HIV and Tuberculosis (TB) consultations in clinics and hospitals in the Eastern Cape, South Africa. This study forms part of a larger study in which we hope to identify problems and solutions in healthcare communication where healthcare providers and patients do not speak the same language. With your assistance we hope to gain insight from academics, healthcare providers, patients and interpreters to find out what helpful and practical solutions could be implemented to facilitate better communication in these situations. Permission to conduct this research has been obtained from the Rhodes University Ethical Standards Committee.

I invite you to participate in this study by speaking to me about your experience of communication and healthcare from a researcher's perspective.

In addition to the data collected from interviews with researchers such as yourself, the following data will also be collected:

1. Interviews with members of healthcare centre management, healthcare providers, patients receiving treatment for HIV and/or TB, and interpreters.
2. Questionnaires completed by patients receiving treatment for HIV and/or TB.
3. Audio recordings of consultations with patients receiving treatment for HIV and/or TB.

Your participation in this study is completely voluntary. If you agree to participate, you may stop at any time and discontinue your participation. You may also choose whether you would like to be anonymous or named, or if you wish for the interview to be confidential.

All recordings relating to this research, including the recording from this interview, will be kept in a safe place and will only be accessed by researchers on the project. All audio recordings and personally-identifying documents relating to anonymous participants will be destroyed when the research is completed. Data that does not contain personal information will be kept for a maximum of five years after the research has been completed, and may be used for other similar research.

If you have any questions about this study, please feel free to ask me. In addition, if there are questions that you feel I have not answered, or if you have concerns about the research, you may contact Prof Russell Kaschula, the principal researcher, at Rhodes University by calling him on (046) 603 8222 or emailing r.kaschula@ru.ac.za.

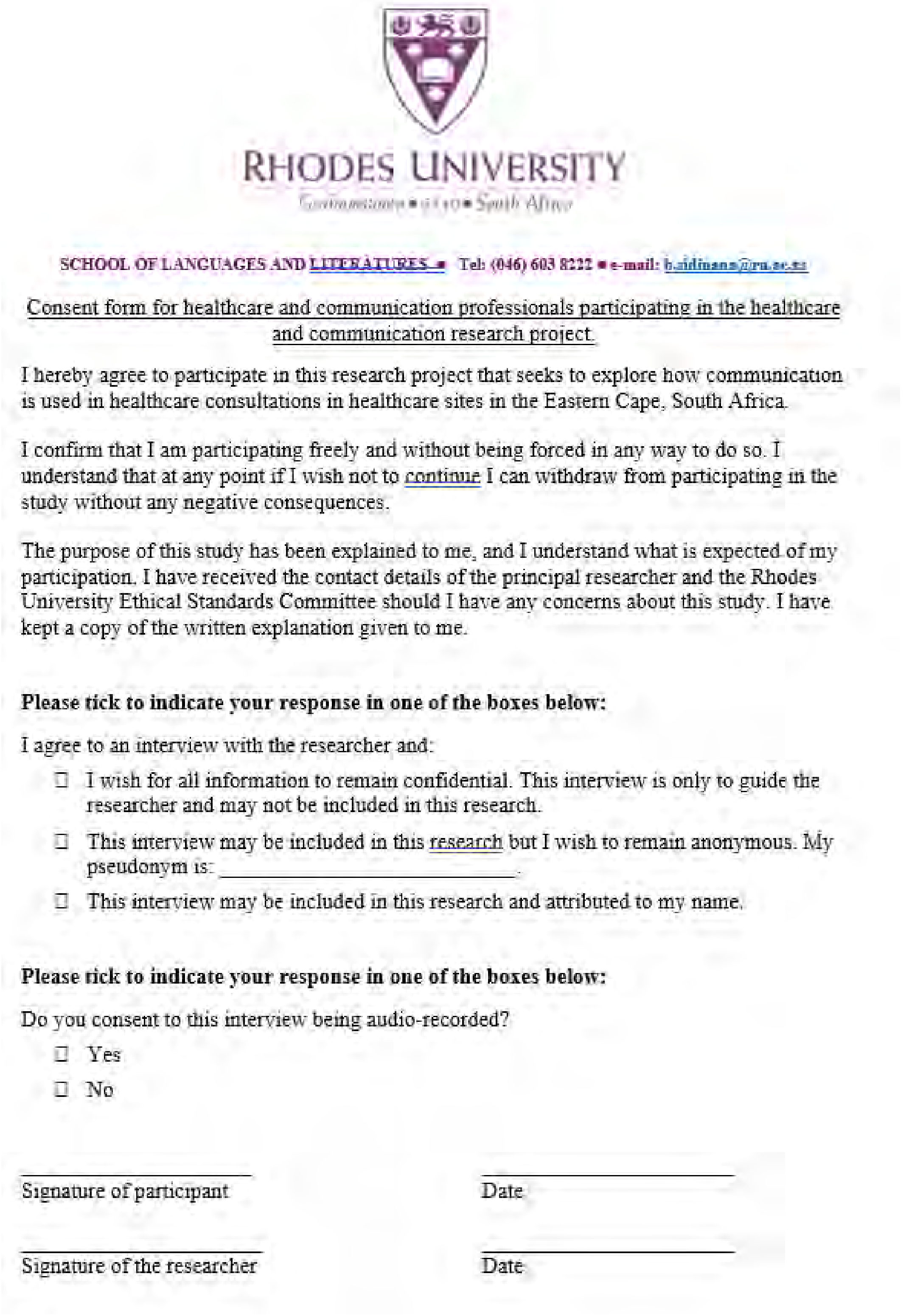
If you have a complaint about any aspect of this study, you may also contact the Rhodes University Ethical Standards Committee by calling (046) 603 8055 or e-mailing ethics-committee@ru.ac.za.

Whether or not you choose to participate in this research, we thank you for your time and consideration.

Yours sincerely,

N. von Witt

Nathalia von Witt
Email: nvonwitt5@gmail.com



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Consent form for healthcare and communication professionals participating in the healthcare and communication research project.

I hereby agree to participate in this research project that seeks to explore how communication is used in healthcare consultations in healthcare sites in the Eastern Cape, South Africa.

I confirm that I am participating freely and without being forced in any way to do so. I understand that at any point if I wish not to continue I can withdraw from participating in the study without any negative consequences.

The purpose of this study has been explained to me, and I understand what is expected of my participation. I have received the contact details of the principal researcher and the Rhodes University Ethical Standards Committee should I have any concerns about this study. I have kept a copy of the written explanation given to me.

Please tick to indicate your response in one of the boxes below:

I agree to an interview with the researcher and:

☐ I wish for all information to remain confidential. This interview is only to guide the researcher and may not be included in this research.

☐ This interview may be included in this research but I wish to remain anonymous. My pseudonym is: ____________________________.

☐ This interview may be included in this research and attributed to my name.

Please tick to indicate your response in one of the boxes below:

Do you consent to this interview being audio-recorded?

☐ Yes

☐ No

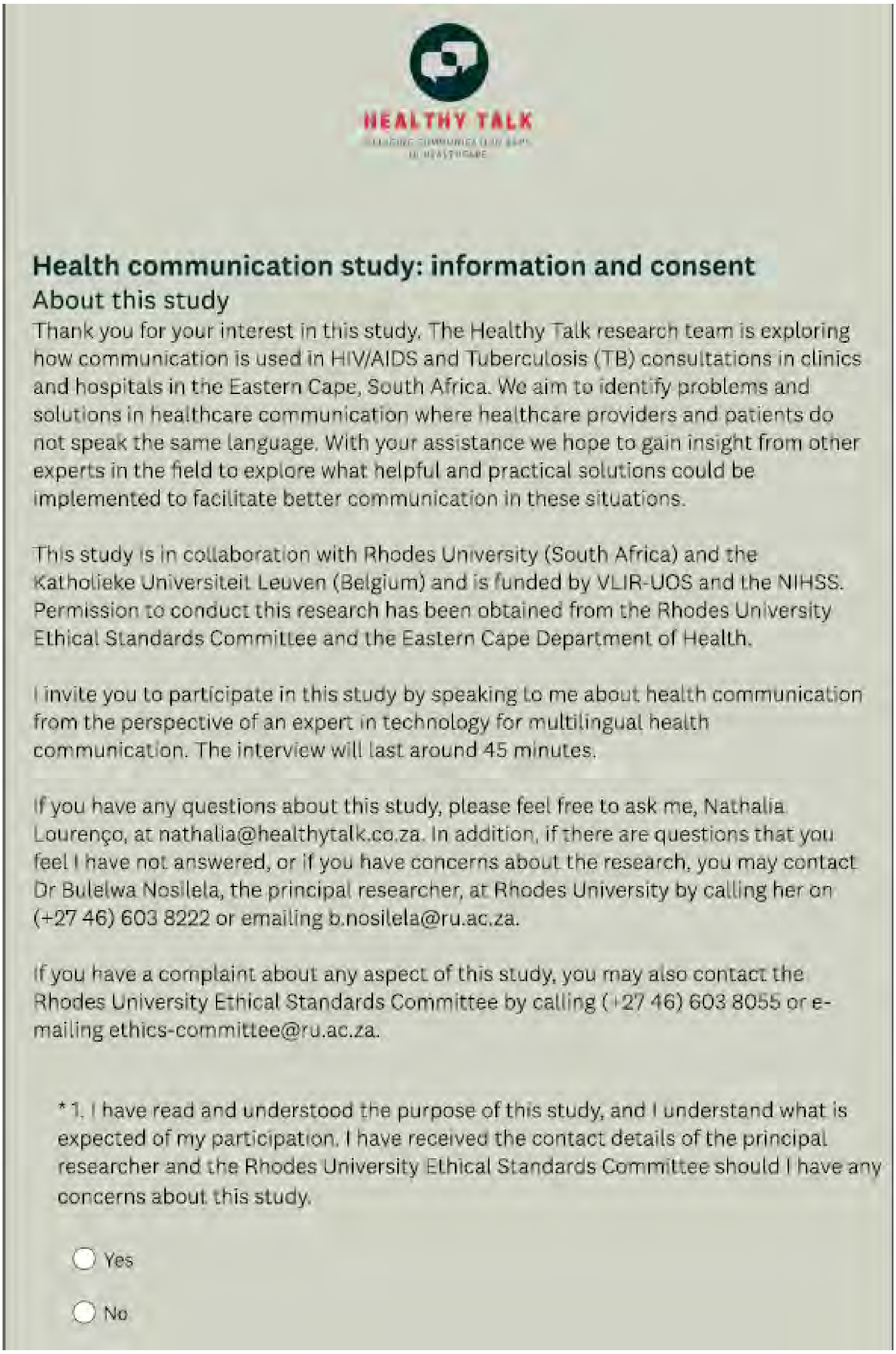
______________________ ______________________
Signature of participant Date

______________________ ______________________
Signature of the researcher Date

Appendix 6: Information sheet and consent form for interviews with health communication experts (online)

This information sheet and consent form can also be accessed online here:

<https://www.surveymonkey.com/r/HealthyTalk08>



Health communication study: information and consent

About this study

Thank you for your interest in this study. The Healthy Talk research team is exploring how communication is used in HIV/AIDS and Tuberculosis (TB) consultations in clinics and hospitals in the Eastern Cape, South Africa. We aim to identify problems and solutions in healthcare communication where healthcare providers and patients do not speak the same language. With your assistance we hope to gain insight from other experts in the field to explore what helpful and practical solutions could be implemented to facilitate better communication in these situations.

This study is in collaboration with Rhodes University (South Africa) and the Katholieke Universiteit Leuven (Belgium) and is funded by VLIR-UOS and the NIHSS. Permission to conduct this research has been obtained from the Rhodes University Ethical Standards Committee and the Eastern Cape Department of Health.

I invite you to participate in this study by speaking to me about health communication from the perspective of an expert in technology for multilingual health communication. The interview will last around 45 minutes.

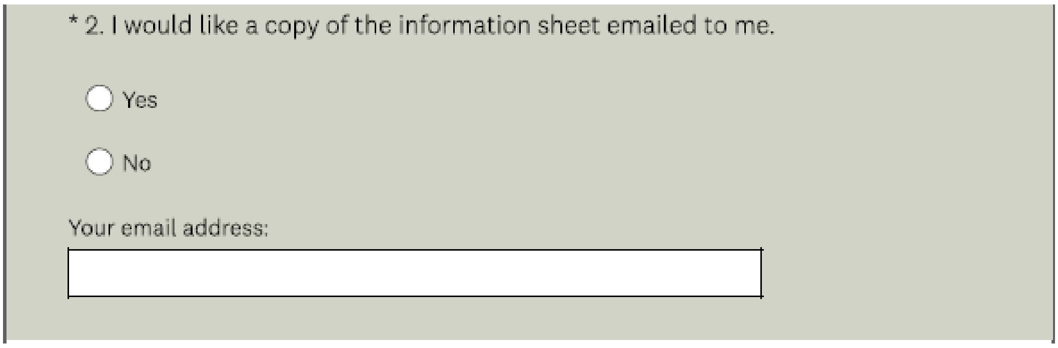
If you have any questions about this study, please feel free to ask me, Nathalia Lourenço, at nathalia@healthytalk.co.za. In addition, if there are questions that you feel I have not answered, or if you have concerns about the research, you may contact Dr Bulelwa Nosilela, the principal researcher, at Rhodes University by calling her on (+27 46) 603 8222 or emailing b.nosilela@ru.ac.za.

If you have a complaint about any aspect of this study, you may also contact the Rhodes University Ethical Standards Committee by calling (+27 46) 603 8055 or e-mailing ethics-committee@ru.ac.za.

* 1. I have read and understood the purpose of this study, and I understand what is expected of my participation. I have received the contact details of the principal researcher and the Rhodes University Ethical Standards Committee should I have any concerns about this study.

○ Yes

○ No



* 2. I would like a copy of the information sheet emailed to me.

○ Yes

○ No

Your email address:

Appendix 7: Information and consent form for HCPs participating in the needs analysis study

This information sheet and consent form can also be accessed online here:

<https://www.surveymonkey.com/r/HealthyTalk02>

Healthcare Communication

Welcome to the study

Thank you for your interest in this study. This study is about how communication is used in HIV/AIDS and Tuberculosis (TB) consultations in South Africa. All healthcare workers (doctors, nurses, pharmacists, community health workers etc) who provide healthcare for people living with HIV/AIDS and/or TB are invited to participate.

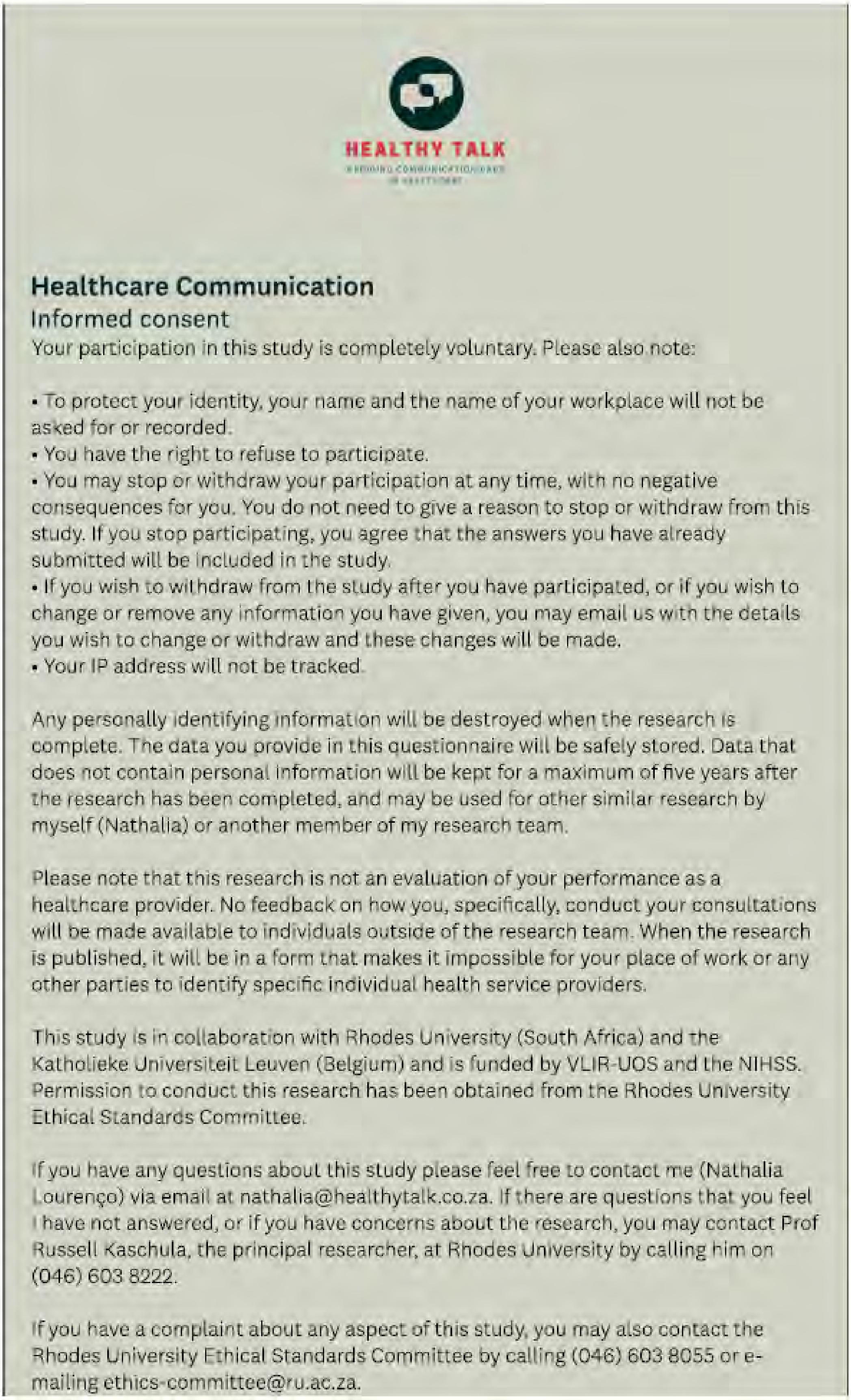
This study forms part of a larger study in which we hope to identify problems and solutions in healthcare communication where healthcare providers and patients do not speak the same language. With your assistance we hope to gain insight from healthcare providers to find out what helpful and practical solutions could be implemented to facilitate better communication in these situations. The input we receive from these questionnaires will assist us in creating communication resources, which we will trial at a later point in this study.

This questionnaire will ask you about your experiences of communication as a healthcare provider. It should take you about 10 to 15 minutes to complete, depending on the amount of detail you wish to give.

* 1. Do you provide healthcare for people living with HIV/AIDS and/or TB?

○ Yes

○ No



HEALTHY TALK

Healthcare Communication

Informed consent

Your participation in this study is completely voluntary. Please also note:

- To protect your identity, your name and the name of your workplace will not be asked for or recorded.
- You have the right to refuse to participate.
- You may stop or withdraw your participation at any time, with no negative consequences for you. You do not need to give a reason to stop or withdraw from this study. If you stop participating, you agree that the answers you have already submitted will be included in the study.
- If you wish to withdraw from the study after you have participated, or if you wish to change or remove any information you have given, you may email us with the details you wish to change or withdraw and these changes will be made.
- Your IP address will not be tracked.

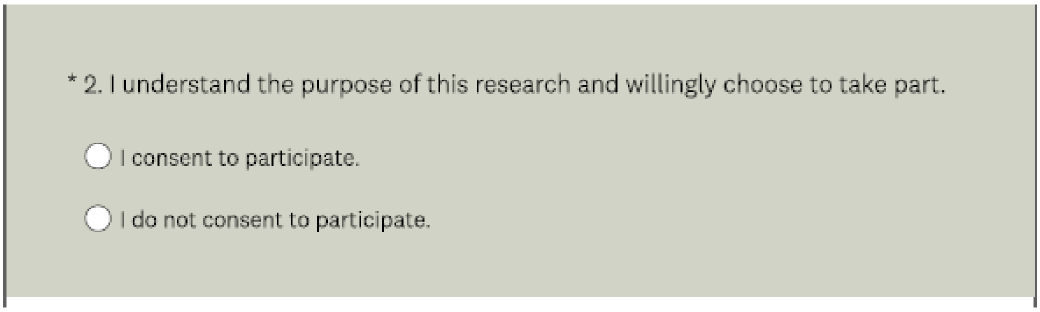
Any personally identifying information will be destroyed when the research is complete. The data you provide in this questionnaire will be safely stored. Data that does not contain personal information will be kept for a maximum of five years after the research has been completed, and may be used for other similar research by myself (Nathalia) or another member of my research team.

Please note that this research is not an evaluation of your performance as a healthcare provider. No feedback on how you, specifically, conduct your consultations will be made available to individuals outside of the research team. When the research is published, it will be in a form that makes it impossible for your place of work or any other parties to identify specific individual health service providers.

This study is in collaboration with Rhodes University (South Africa) and the Katholieke Universiteit Leuven (Belgium) and is funded by VLIR-UOS and the NIHSS. Permission to conduct this research has been obtained from the Rhodes University Ethical Standards Committee.

If you have any questions about this study please feel free to contact me (Nathalia Lourenço) via email at nathalia@healthytalk.co.za. If there are questions that you feel I have not answered, or if you have concerns about the research, you may contact Prof Russell Kaschula, the principal researcher, at Rhodes University by calling him on (046) 603 8222.

If you have a complaint about any aspect of this study, you may also contact the Rhodes University Ethical Standards Committee by calling (046) 603 8055 or e-mailing ethics-committee@ru.ac.za.



* 2. I understand the purpose of this research and willingly choose to take part.

○ I consent to participate.

○ I do not consent to participate.

Appendix 8: Information and consent form for HCP questionnaire on proposed resources

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Grahamstown • 6140 • South Africa

SCHOOL OF LANGUAGES AND LITERATURES ● Tel: (046) 603 8222 ● e-mail: b.sidinana@ru.ac.za

June 2021

Dear Healthcare Professional,

I am Nathalia Lourenço, a PhD candidate from Rhodes University and KU Leuven, working on the Healthy Talk health communication study. I am part of a research team interested in how communication is used in HIV/AIDS and Tuberculosis (TB) consultations in hospitals in the Eastern Cape, South Africa, and what resources and training are best suited to support healthcare professionals (HCPs) and patients communicate across language barriers. You can read more about us at healthytalk.co.za. With your assistance we hope to gain insight from healthcare providers to find out what helpful and practical solutions could be implemented to facilitate better communication in these situations. All HCPs who provide healthcare services for people living with HIV/AIDS and/or TB as part of their practice are invited to participate.

Participation in the study will involve the following:

1. Giving feedback on suggested resources via a questionnaire.
2. Completing bite-sized online training via your phone or computer.
3. Trialing paper-based and/or digital communication resources in your consultations.
4. Completing three short (5-10 minute) questionnaires over a two-month period about communication in your consultations.

Your participation in this study is completely voluntary, and you have the right to refuse to participate. You may stop or withdraw your participation at any time, with no negative consequences for you. You do not need to give a reason to stop or withdraw from this study. Please note that this research is not an evaluation of your performance as a healthcare provider.

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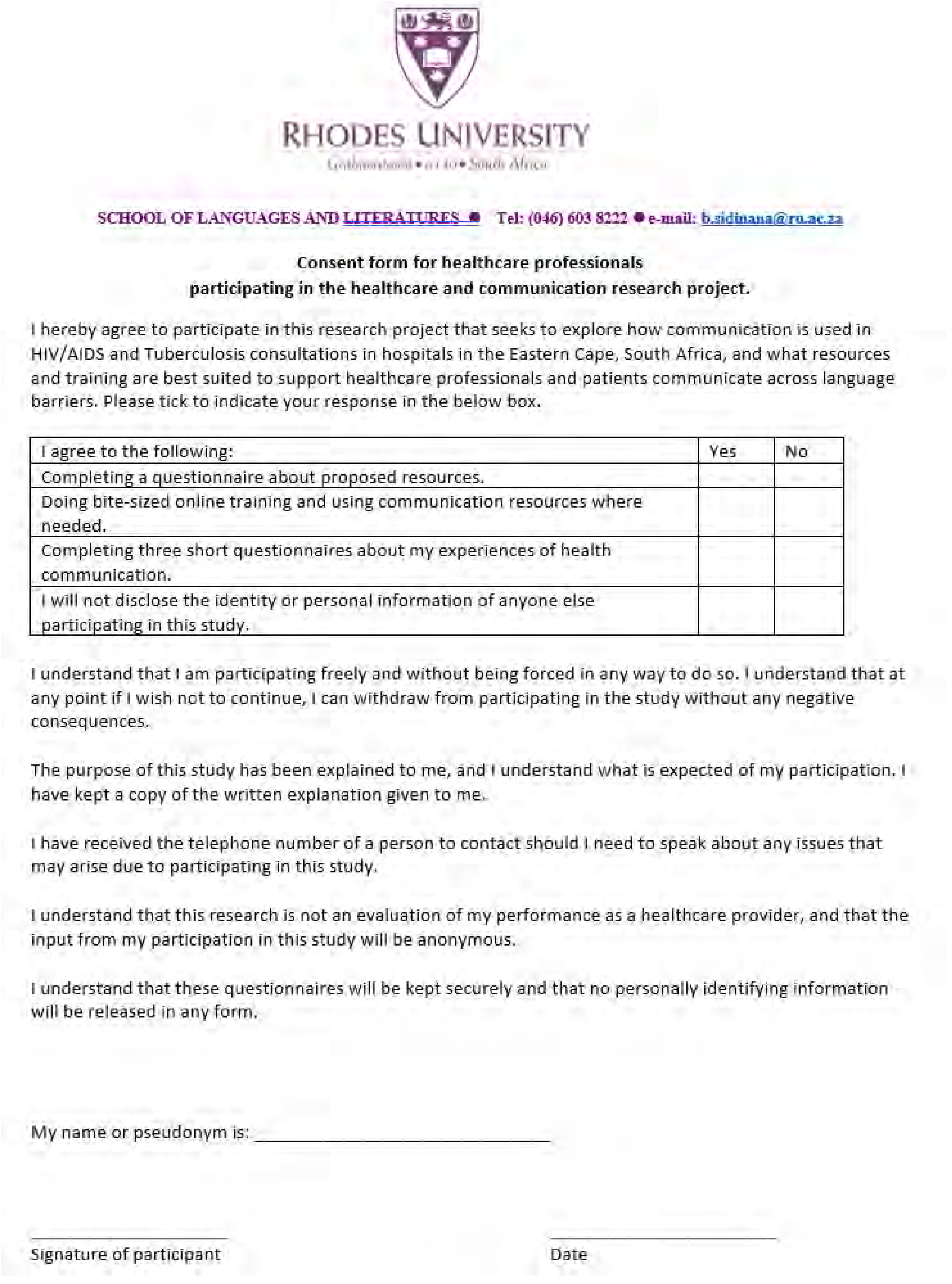
Please keep this page for your reference.

Whether or not you choose to participate in this research, we thank you for your time and consideration.

Yours sincerely,
Nathalia Lourenço



RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

SCHOOL OF LANGUAGES AND LITERATURES ● Tel: (046) 603 8222 ● e-mail: b.sidinana@ru.ac.za

Consent form for healthcare professionals participating in the healthcare and communication research project.

I hereby agree to participate in this research project that seeks to explore how communication is used in HIV/AIDS and Tuberculosis consultations in hospitals in the Eastern Cape, South Africa, and what resources and training are best suited to support healthcare professionals and patients communicate across language barriers. Please tick to indicate your response in the below box.

I agree to the following:	Yes	No
Completing a questionnaire about proposed resources.		
Doing bite-sized online training and using communication resources where needed.		
Completing three short questionnaires about my experiences of health communication.		
I will not disclose the identity or personal information of anyone else participating in this study.		

I understand that I am participating freely and without being forced in any way to do so. I understand that at any point if I wish not to continue, I can withdraw from participating in the study without any negative consequences.

The purpose of this study has been explained to me, and I understand what is expected of my participation. I have kept a copy of the written explanation given to me.

I have received the telephone number of a person to contact should I need to speak about any issues that may arise due to participating in this study.

I understand that this research is not an evaluation of my performance as a healthcare provider, and that the input from my participation in this study will be anonymous.

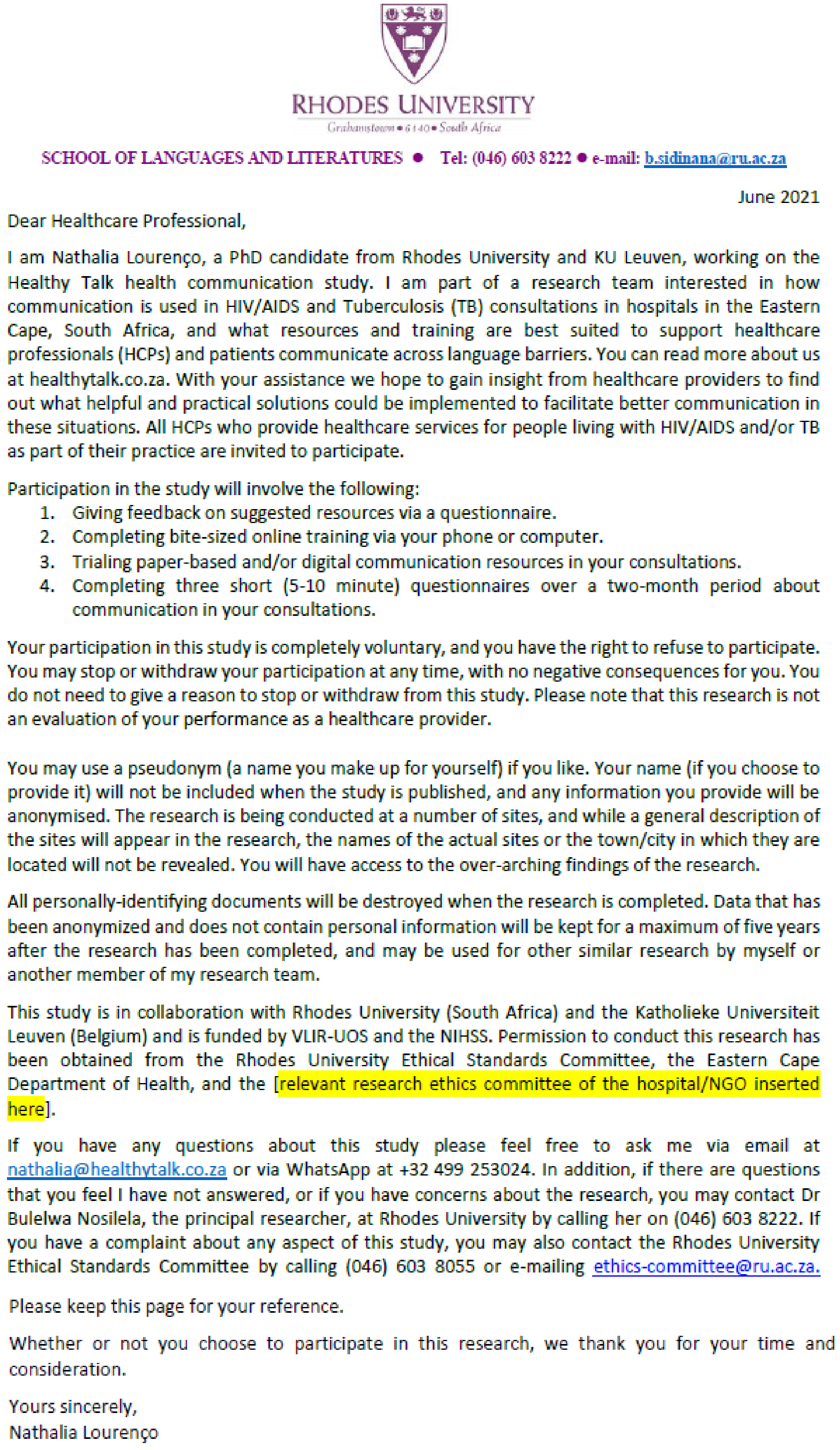
I understand that these questionnaires will be kept securely and that no personally identifying information will be released in any form.

My name or pseudonym is: ______________________________

____
Signature of participant

____
Date

Appendix 9: Information and consent form for HCP focus group discussion on proposed resources



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Grahamstown • 6140 • South Africa

SCHOOL OF LANGUAGES AND LITERATURES ● **Tel: (046) 603 8222** ● **e-mail: b.sidinana@ru.ac.za**

June 2021

Dear Healthcare Professional,

I am Nathalia Lourenço, a PhD candidate from Rhodes University and KU Leuven, working on the Healthy Talk health communication study. I am part of a research team interested in how communication is used in HIV/AIDS and Tuberculosis (TB) consultations in hospitals in the Eastern Cape, South Africa, and what resources and training are best suited to support healthcare professionals (HCPs) and patients communicate across language barriers. You can read more about us at healthytalk.co.za. With your assistance we hope to gain insight from healthcare providers to find out what helpful and practical solutions could be implemented to facilitate better communication in these situations. All HCPs who provide healthcare services for people living with HIV/AIDS and/or TB as part of their practice are invited to participate.

Participation in the study will involve the following:

1. Giving feedback on suggested resources via a questionnaire.
2. Completing bite-sized online training via your phone or computer.
3. Trialing paper-based and/or digital communication resources in your consultations.
4. Completing three short (5-10 minute) questionnaires over a two-month period about communication in your consultations.

Your participation in this study is completely voluntary, and you have the right to refuse to participate. You may stop or withdraw your participation at any time, with no negative consequences for you. You do not need to give a reason to stop or withdraw from this study. Please note that this research is not an evaluation of your performance as a healthcare provider.

You may use a pseudonym (a name you make up for yourself) if you like. Your name (if you choose to provide it) will not be included when the study is published, and any information you provide will be anonymised. The research is being conducted at a number of sites, and while a general description of the sites will appear in the research, the names of the actual sites or the town/city in which they are located will not be revealed. You will have access to the over-arching findings of the research.

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I hereby agree to participate in this research project that seeks to explore how communication is used in HIV/AIDS and Tuberculosis consultations in hospitals in the Eastern Cape, South Africa, and what resources and training are best suited to support healthcare professionals and patients communicate across language barriers. Please tick to indicate your response in the below box.

I agree to the following:	Yes	No
Participating in a focus group discussion about proposed resources, via a recorded video call on Zoom.		
Doing bite-sized online training and using communication resources where needed.		
Completing three short questionnaires about my experiences of health communication.		
I will not disclose the identity or personal information of anyone else participating in this study.		

I understand that I am participating freely and without being forced in any way to do so. I understand that at any point if I wish not to continue, I can withdraw from participating in the study without any negative consequences.

The purpose of this study has been explained to me, and I understand what is expected of my participation. I have kept a copy of the written explanation given to me.

I have received the telephone number of a person to contact should I need to speak about any issues that may arise due to participating in this study.

I understand that this research is not an evaluation of my performance as a healthcare provider, and that the input from my participation in this study will be anonymous.

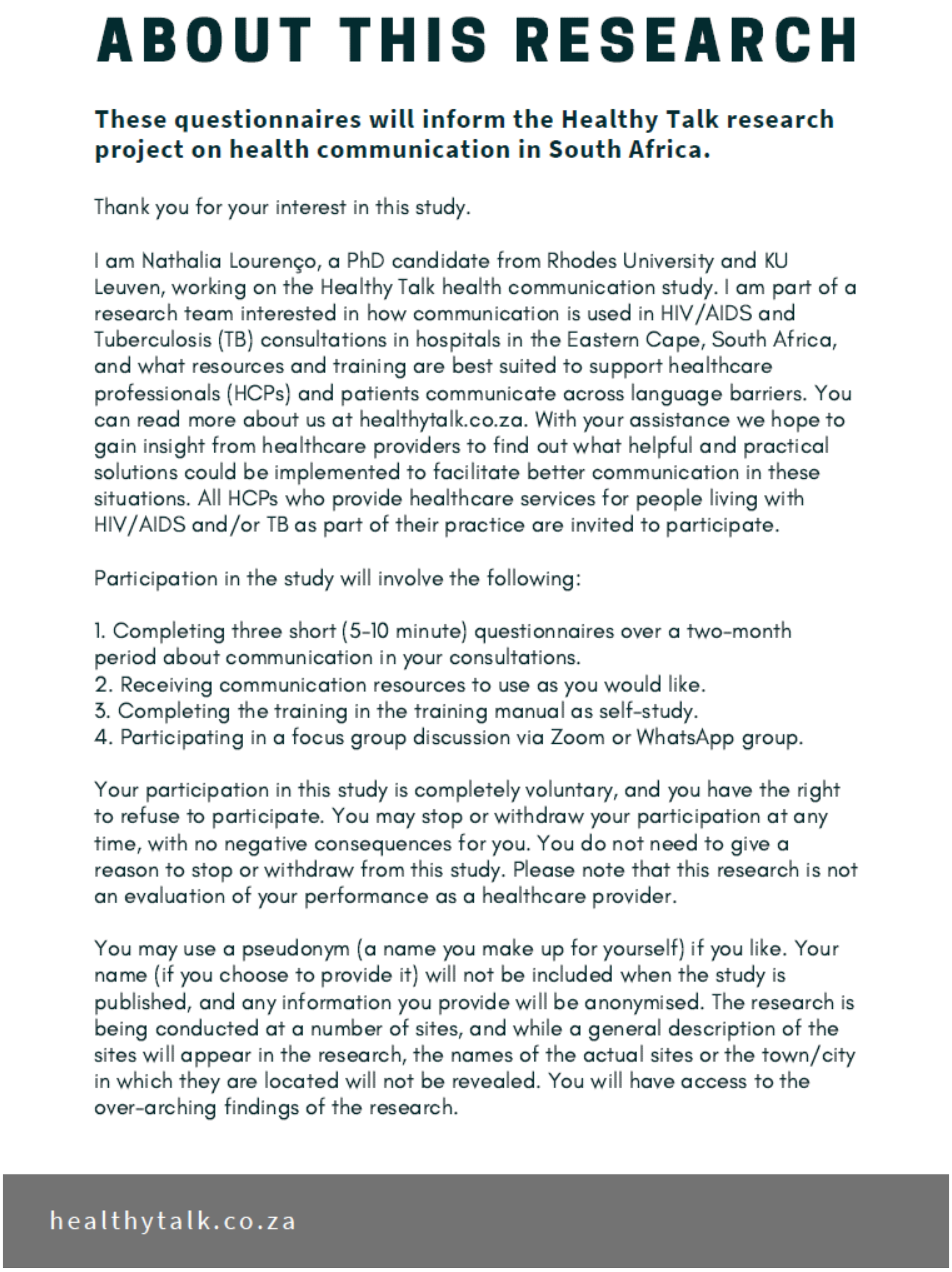
I understand that the recording of the focus group will be kept securely and that no personally identifying information will be released in any form.

My name or pseudonym is: ______________________________

______________________ ______________________
Signature of participant Date

Appendix 10: Information and consent form for pilot feasibility trial (intervention group)

Participating HCPs in the intervention group received this information sheet and consent form together with the resource pack.



ABOUT THIS RESEARCH

These questionnaires will inform the Healthy Talk research project on health communication in South Africa.

Thank you for your interest in this study.

I am Nathalia Lourenço, a PhD candidate from Rhodes University and KU Leuven, working on the Healthy Talk health communication study. I am part of a research team interested in how communication is used in HIV/AIDS and Tuberculosis (TB) consultations in hospitals in the Eastern Cape, South Africa, and what resources and training are best suited to support healthcare professionals (HCPs) and patients communicate across language barriers. You can read more about us at healthytalk.co.za. With your assistance we hope to gain insight from healthcare providers to find out what helpful and practical solutions could be implemented to facilitate better communication in these situations. All HCPs who provide healthcare services for people living with HIV/AIDS and/or TB as part of their practice are invited to participate.

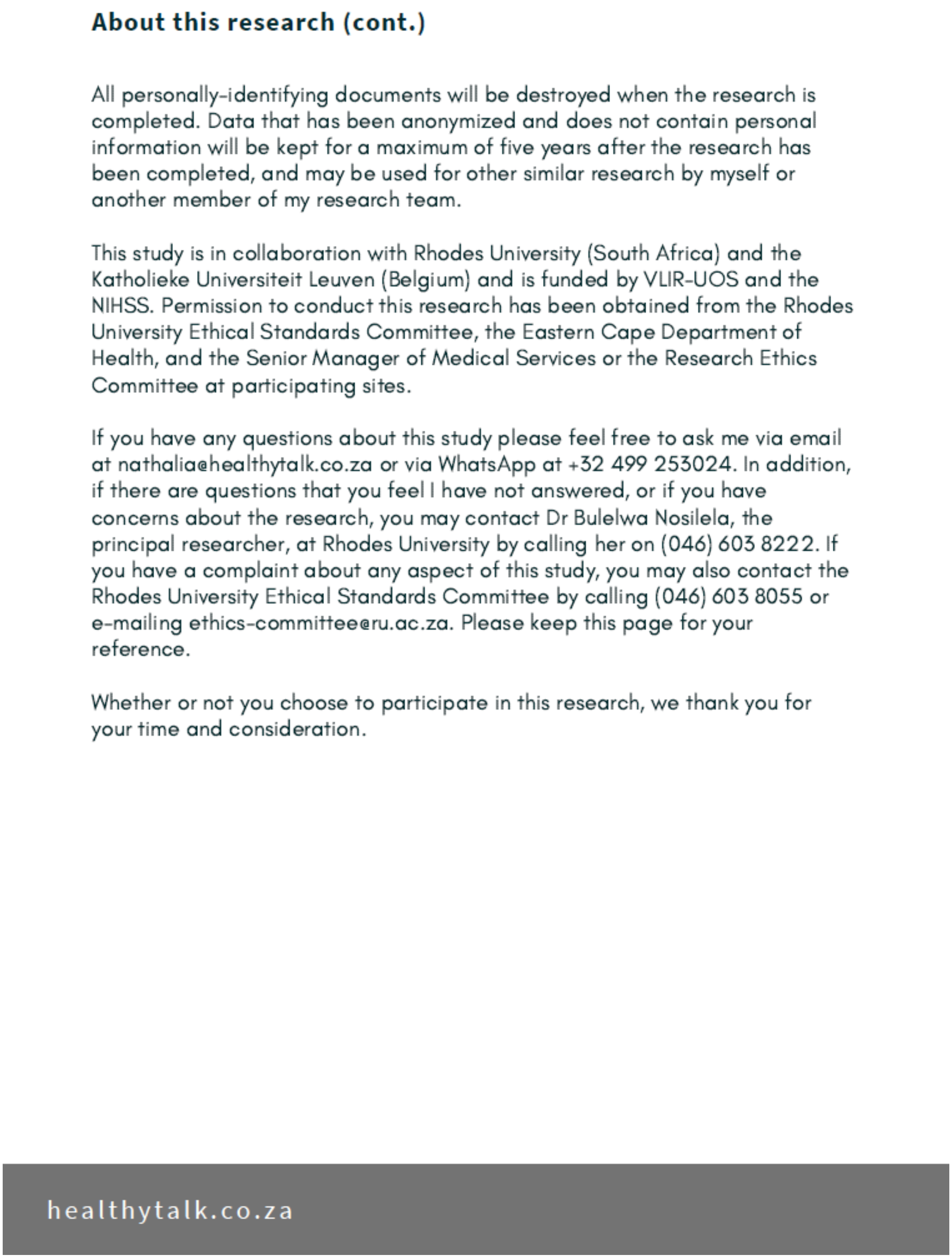
Participation in the study will involve the following:

1. Completing three short (5-10 minute) questionnaires over a two-month period about communication in your consultations.
2. Receiving communication resources to use as you would like.
3. Completing the training in the training manual as self-study.
4. Participating in a focus group discussion via Zoom or WhatsApp group.

Your participation in this study is completely voluntary, and you have the right to refuse to participate. You may stop or withdraw your participation at any time, with no negative consequences for you. You do not need to give a reason to stop or withdraw from this study. Please note that this research is not an evaluation of your performance as a healthcare provider.

You may use a pseudonym (a name you make up for yourself) if you like. Your name (if you choose to provide it) will not be included when the study is published, and any information you provide will be anonymised. The research is being conducted at a number of sites, and while a general description of the sites will appear in the research, the names of the actual sites or the town/city in which they are located will not be revealed. You will have access to the over-arching findings of the research.

healthytalk.co.za



About this research (cont.)

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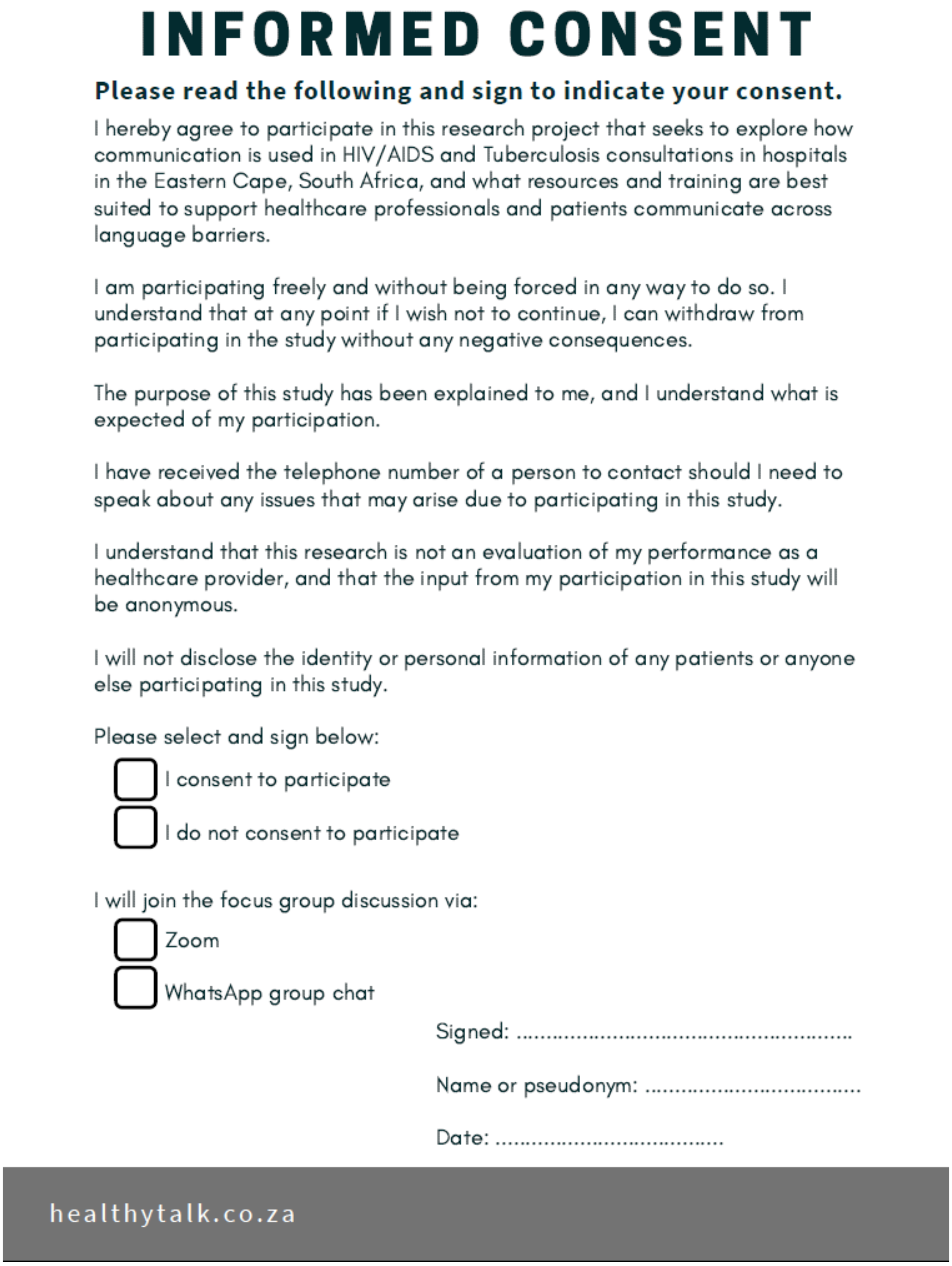
If you have any questions about this study please feel free to ask me via email at nathalia@healthytalk.co.za or via WhatsApp at +32 499 253024. In addition, if there are questions that you feel I have not answered, or if you have concerns about the research, you may contact Dr Bulelwa Nosilela, the principal researcher, at Rhodes University by calling her on (046) 603 8222. If you have a complaint about any aspect of this study, you may also contact the Rhodes University Ethical Standards Committee by calling (046) 603 8055 or e-mailing ethics-committee@ru.ac.za. Please keep this page for your reference.

Whether or not you choose to participate in this research, we thank you for your time and consideration.

healthytalk.co.za



INFORMED CONSENT

Please read the following and sign to indicate your consent.

I hereby agree to participate in this research project that seeks to explore how communication is used in HIV/AIDS and Tuberculosis consultations in hospitals in the Eastern Cape, South Africa, and what resources and training are best suited to support healthcare professionals and patients communicate across language barriers.

I am participating freely and without being forced in any way to do so. I understand that at any point if I wish not to continue, I can withdraw from participating in the study without any negative consequences.

The purpose of this study has been explained to me, and I understand what is expected of my participation.

I have received the telephone number of a person to contact should I need to speak about any issues that may arise due to participating in this study.

I understand that this research is not an evaluation of my performance as a healthcare provider, and that the input from my participation in this study will be anonymous.

I will not disclose the identity or personal information of any patients or anyone else participating in this study.

Please select and sign below:

☐ I consent to participate

☐ I do not consent to participate

I will join the focus group discussion via:

☐ Zoom

☐ WhatsApp group chat

Signed: ……………………………………………….

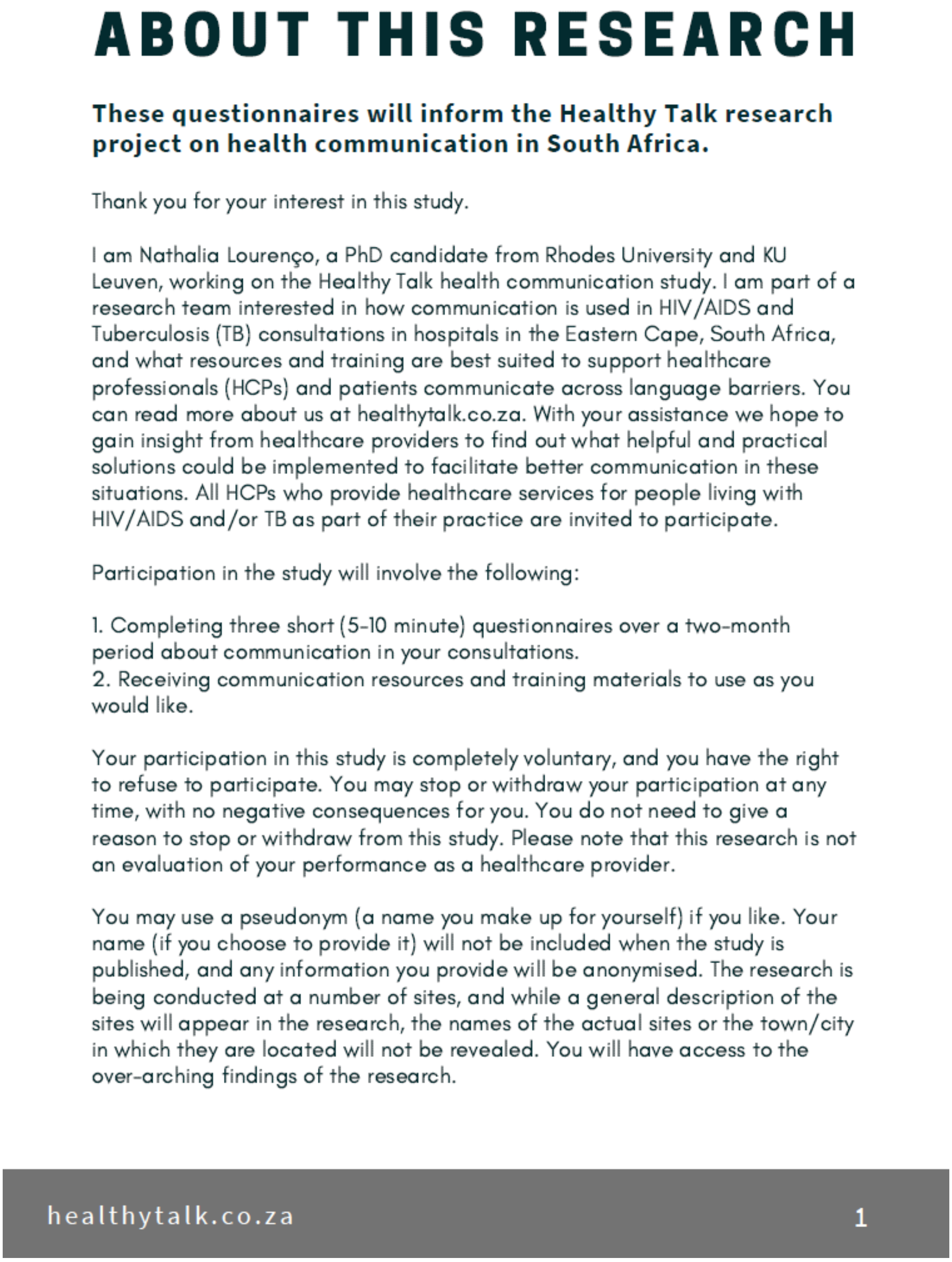
Name or pseudonym: ………………………………

Date: …………………………………

healthytalk.co.za

Appendix 11: Information and consent form for pilot feasibility trial (control group)

Participating HCPs in the control group received this information sheet and consent form included in their questionnaire booklets.



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Participation in the study will involve the following:

1. Completing three short (5-10 minute) questionnaires over a two-month period about communication in your consultations.
2. Receiving communication resources and training materials to use as you would like.

Your participation in this study is completely voluntary, and you have the right to refuse to participate. You may stop or withdraw your participation at any time, with no negative consequences for you. You do not need to give a reason to stop or withdraw from this study. Please note that this research is not an evaluation of your performance as a healthcare provider.

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healthytalk.co.za 1

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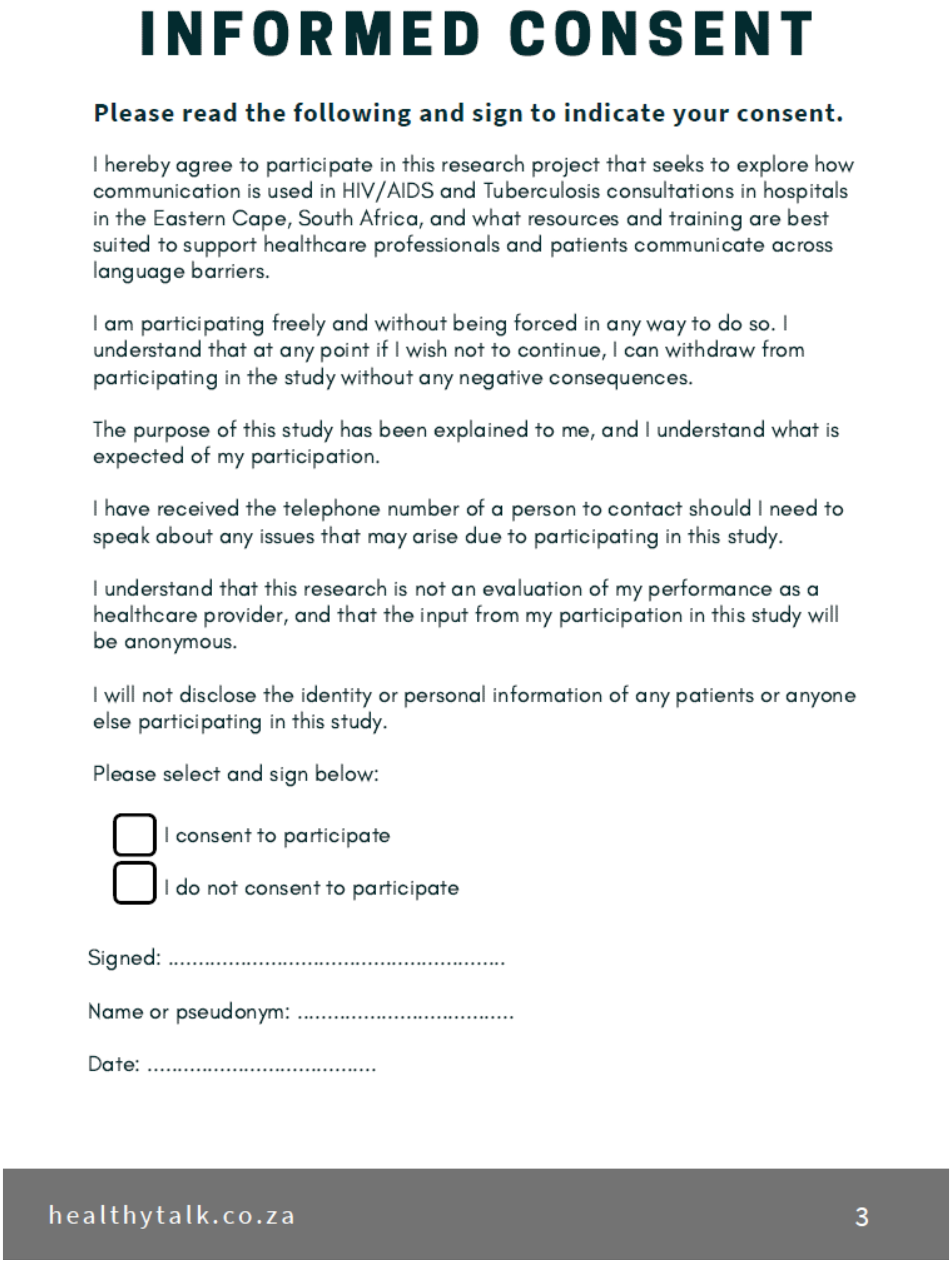

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I am participating freely and without being forced in any way to do so. I understand that at any point if I wish not to continue, I can withdraw from participating in the study without any negative consequences.

The purpose of this study has been explained to me, and I understand what is expected of my participation.

I have received the telephone number of a person to contact should I need to speak about any issues that may arise due to participating in this study.

I understand that this research is not an evaluation of my performance as a healthcare provider, and that the input from my participation in this study will be anonymous.

I will not disclose the identity or personal information of any patients or anyone else participating in this study.

Please select and sign below:

☐ I consent to participate
☐ I do not consent to participate

Signed: ....

Name or pseudonym: ....

Date: ....

Questionnaires and interview schedules

Appendix 12: Guiding questions for interviews with health communication experts

Example interview schedule. The interview was adapted according to the expertise of each participant.

1. Introduction to the study and informed consent.
2. Specific questions about the expert's work or studies, e.g.:
   a. What has been key to making your interventions sustainable?
   b. How are your resources shared?
3. Recommendations for this study, e.g.:
   a. What approaches to implementing training do you think are most feasible? Particularly with regard to when and how it is implemented.
   b. What recommendations do you have from using PAR in your own studies?
4. Thank you and next steps of the research.

Appendix 13: Needs analysis online questionnaire

This questionnaire can be found online at:

< https://www.surveymonkey.com/r/HealthyTalk02 >

HEALTHY TALK

Healthcare Communication

About you

Any information you provide here will remain anonymous.

* 3. What language(s) do you speak at home?

* 4. What other languages are you able to have a conversation in?

* 5. Do you make use of any apps in consultations with your patients?

○ Yes

○ No

* 6. Would you use an app to help you communicate with patients who cannot speak English, if one was available?

○ Yes

○ No

○ Maybe

HEALTHY TALK

Healthcare Communication
Communication app

* 7. What kind of cellphone do you use?

○ iPhone

○ Android

○ Not a smartphone

○ Other (please specify)

* 8. If an app was available to assist with communication in your consultations, which of the following would you use?

☐ An app for HIV/AIDS

☐ An app for TB

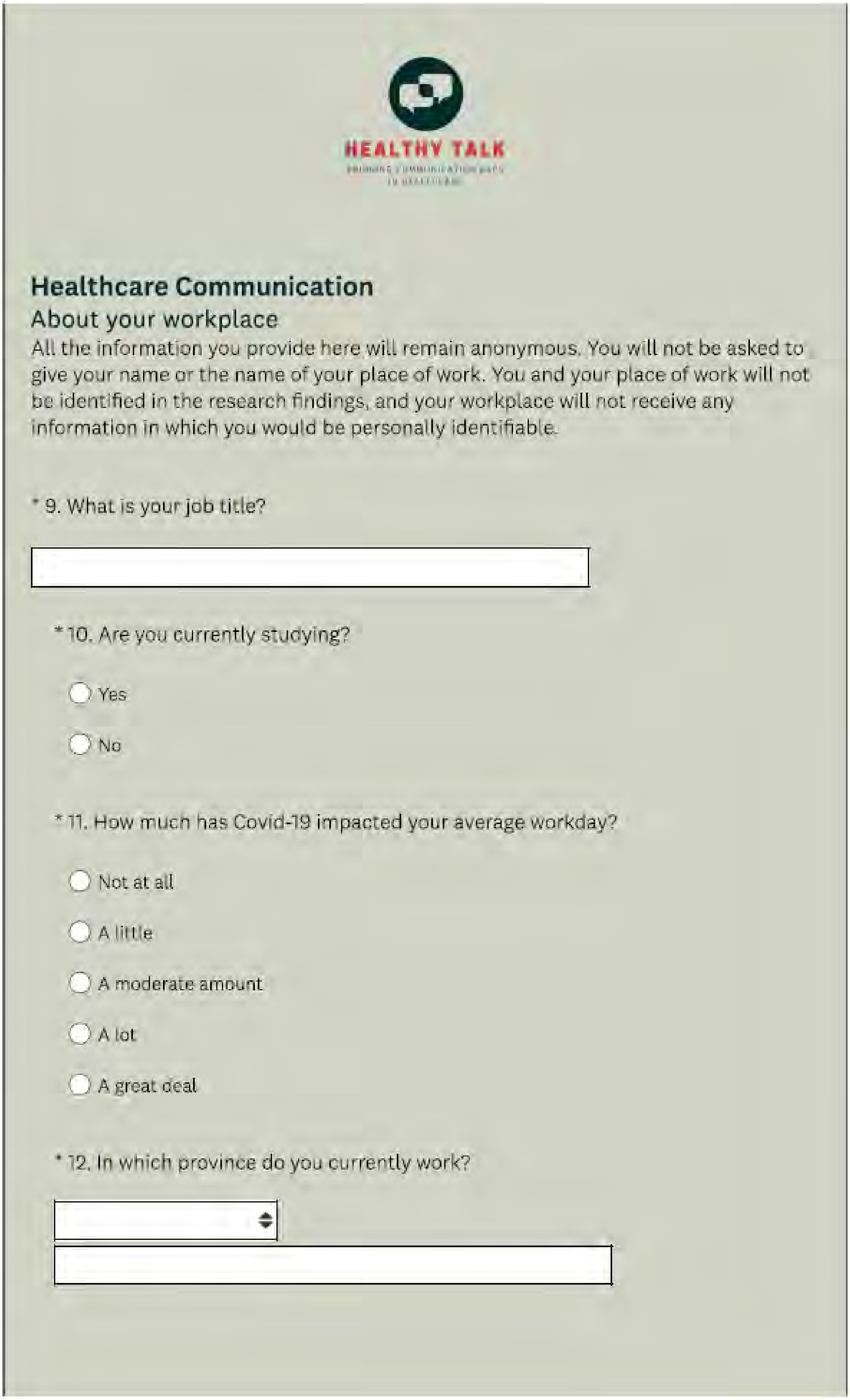
☐ An app for Covid-19

☐ An app for HIV/AIDS and TB

☐ An app for Covid-19 and HIV/AIDS

☐ An app for Covid-19 and TB

☐ An app for Covid-19, HIV/AIDS and TB



Healthcare Communication

About your workplace

All the information you provide here will remain anonymous. You will not be asked to give your name or the name of your place of work. You and your place of work will not be identified in the research findings, and your workplace will not receive any information in which you would be personally identifiable.

* 9. What is your job title?

* 10. Are you currently studying?

○ Yes

○ No

* 11. How much has Covid-19 impacted your average workday?

○ Not at all

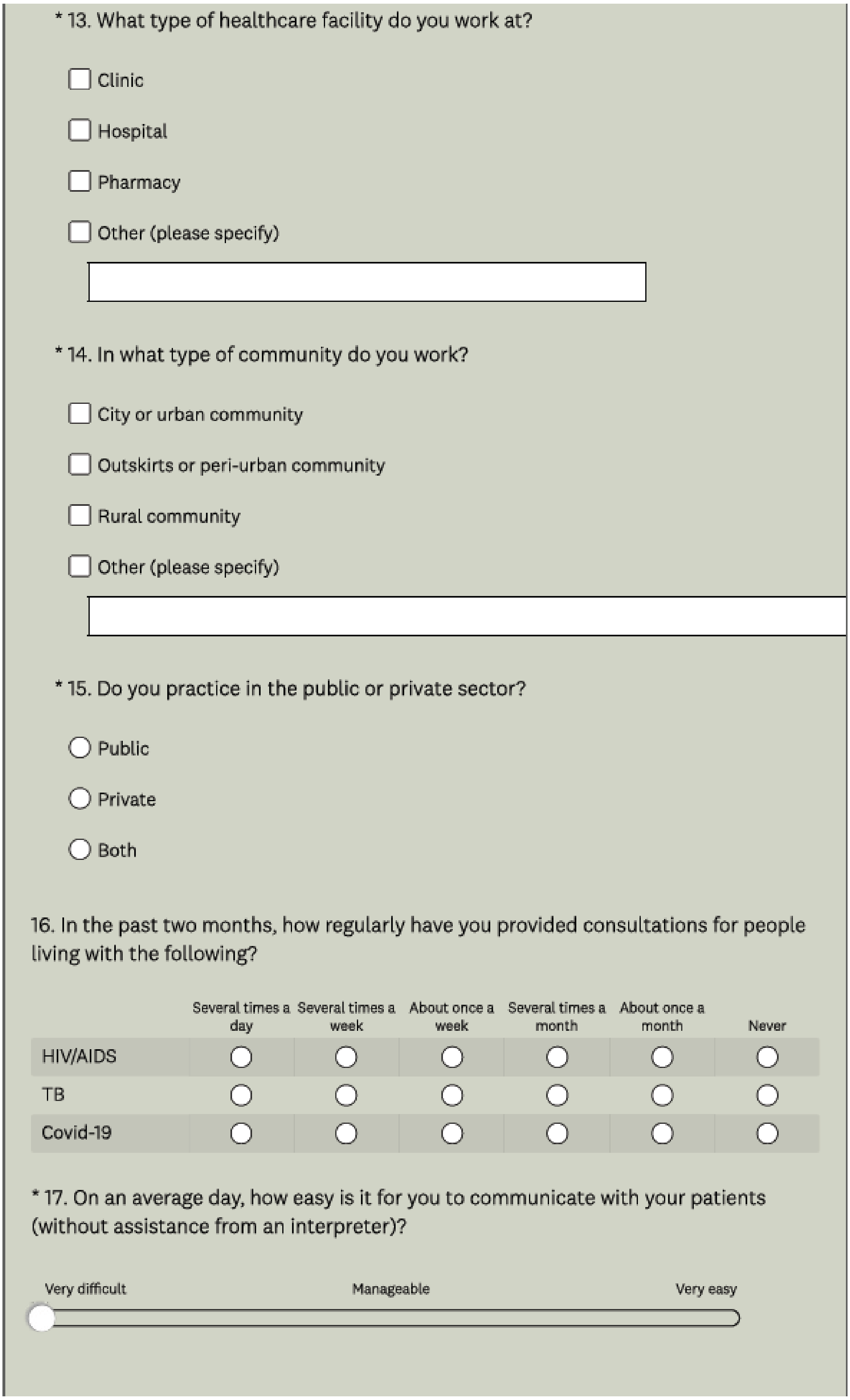
○ A little

○ A moderate amount

○ A lot

○ A great deal

* 12. In which province do you currently work?



* 13. What type of healthcare facility do you work at?

☐ Clinic

☐ Hospital

☐ Pharmacy

☐ Other (please specify)

* 14. In what type of community do you work?

☐ City or urban community

☐ Outskirts or peri-urban community

☐ Rural community

☐ Other (please specify)

* 15. Do you practice in the public or private sector?

○ Public

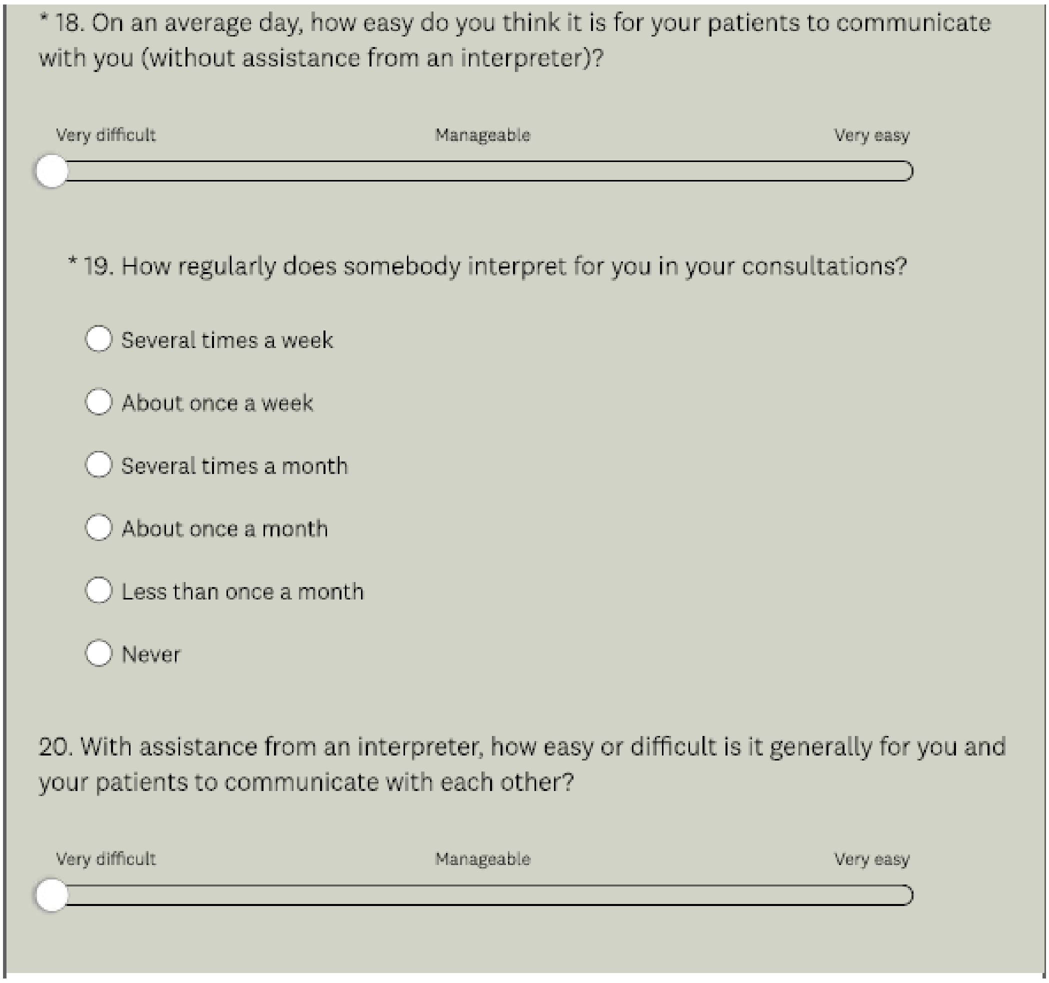
○ Private

○ Both

16. In the past two months, how regularly have you provided consultations for people living with the following?

	Several times a day	Several times a week	About once a week	Several times a month	About once a month	Never
HIV/AIDS	○	○	○	○	○	○
TB	○	○	○	○	○	○
Covid-19	○	○	○	○	○	○

* 17. On an average day, how easy is it for you to communicate with your patients (without assistance from an interpreter)?



* 18. On an average day, how easy do you think it is for your patients to communicate with you (without assistance from an interpreter)?

* 19. How regularly does somebody interpret for you in your consultations?

○ Several times a week

○ About once a week

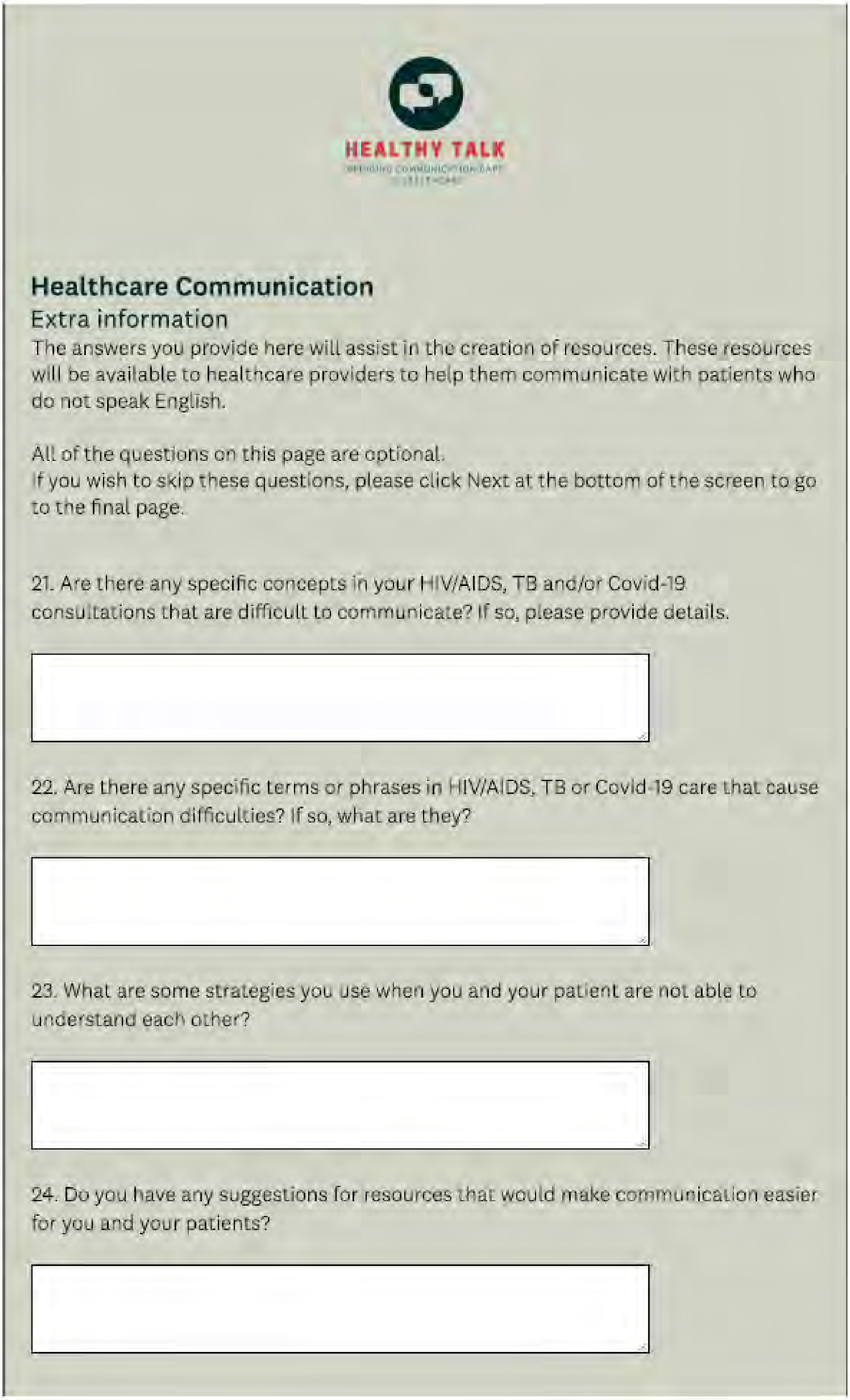
○ Several times a month

○ About once a month

○ Less than once a month

○ Never

20. With assistance from an interpreter, how easy or difficult is it generally for you and your patients to communicate with each other?



HEALTHY TALK

Healthcare Communication

Extra information

The answers you provide here will assist in the creation of resources. These resources will be available to healthcare providers to help them communicate with patients who do not speak English.

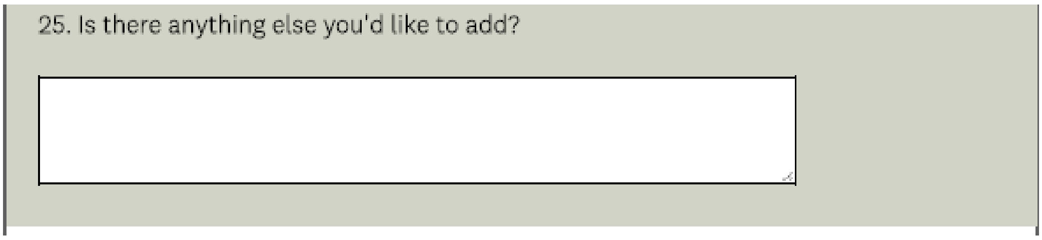
All of the questions on this page are optional.
If you wish to skip these questions, please click Next at the bottom of the screen to go to the final page.

21. Are there any specific concepts in your HIV/AIDS, TB and/or Covid-19 consultations that are difficult to communicate? If so, please provide details.

22. Are there any specific terms or phrases in HIV/AIDS, TB or Covid-19 care that cause communication difficulties? If so, what are they?

23. What are some strategies you use when you and your patient are not able to understand each other?

24. Do you have any suggestions for resources that would make communication easier for you and your patients?



25. Is there anything else you'd like to add?

HEALTHY TALK

Healthcare Communication

Follow-up communication

* 26. Please provide your email address.

Note: Your email address will not be shared and you will only be contacted if you opt in to further communication. If you do not wish to share your email address simply fill in "no."

* 27. Further communication: Please tick all the boxes that apply.

☐ I am happy to be contacted if the researcher has any other questions.

☐ I would like to offer my opinion while the resources are being created.

☐ I want to be updated if a health communication app is made available.

☐ I want to be updated if other health communication resources are made available.

☐ I want to receive a copy of the research results.

☐ I do not want to receive any further communication about this project.

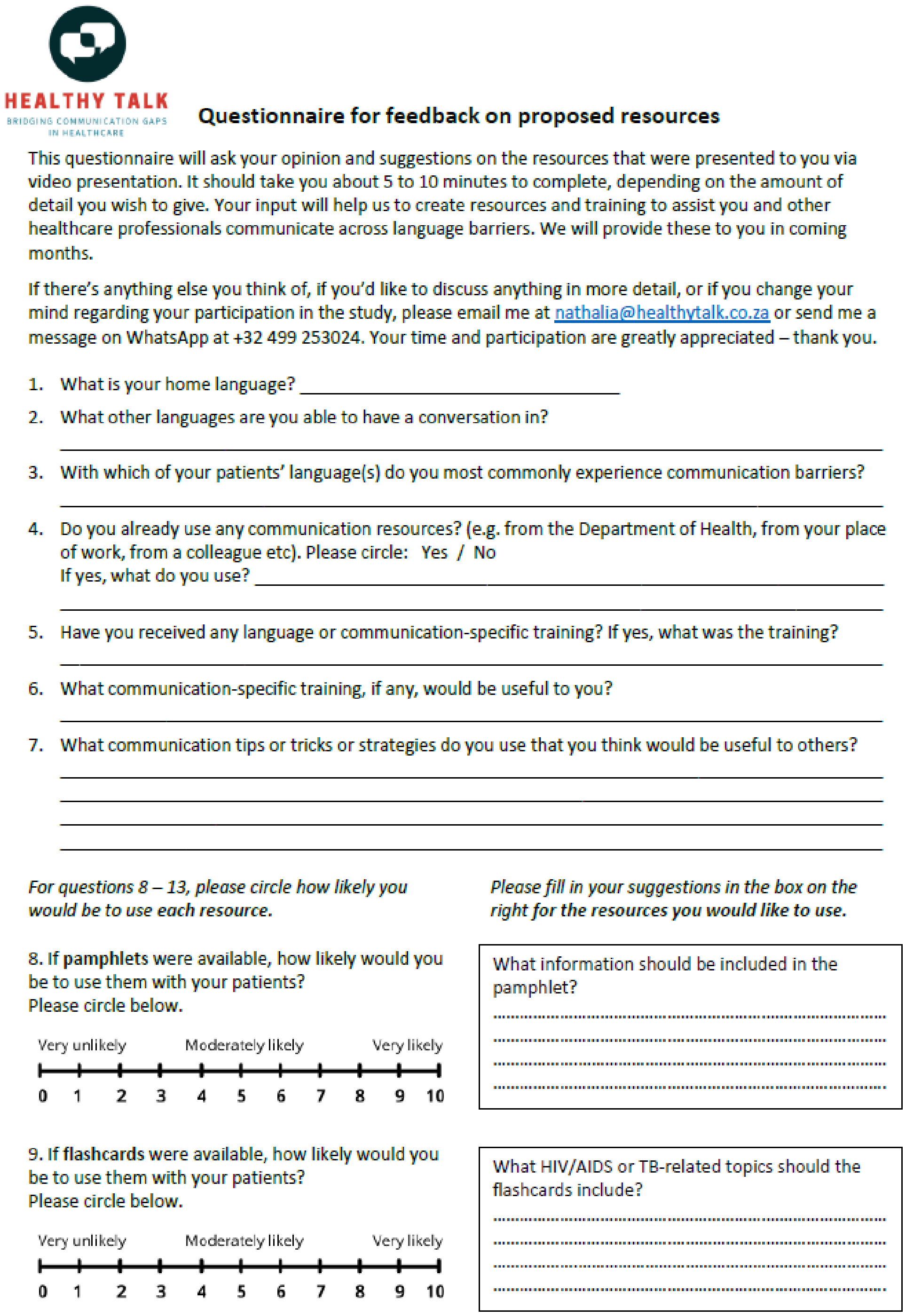
* 28. The next part of this research involves trialling communication resources. Healthcare workers such as yourself will be provided with an app and/or printed materials to facilitate communication with patients across language barriers. This will begin around September 2020.

Would you like to participate in this part of the research?

○ Yes

○ No

Appendix 14: Pilot feasibility questionnaire for feedback on proposed resources



HEALTHY TALK
BRIDGING COMMUNICATION GAPS IN HEALTHCARE

Questionnaire for feedback on proposed resources

This questionnaire will ask your opinion and suggestions on the resources that were presented to you via video presentation. It should take you about 5 to 10 minutes to complete, depending on the amount of detail you wish to give. Your input will help us to create resources and training to assist you and other healthcare professionals communicate across language barriers. We will provide these to you in coming months.

If there's anything else you think of, if you'd like to discuss anything in more detail, or if you change your mind regarding your participation in the study, please email me at nathalia@healthytalk.co.za or send me a message on WhatsApp at +32 499 253024. Your time and participation are greatly appreciated – thank you.

1. What is your home language? ______________________________
2. What other languages are you able to have a conversation in?
   ____
3. With which of your patients' language(s) do you most commonly experience communication barriers?
   ____
4. Do you already use any communication resources? (e.g. from the Department of Health, from your place of work, from a colleague etc). Please circle: Yes / No
   If yes, what do you use? ____
   ____
5. Have you received any language or communication-specific training? If yes, what was the training?
   ____
6. What communication-specific training, if any, would be useful to you?
   ____
7. What communication tips or tricks or strategies do you use that you think would be useful to others?
   ____
   ____
   ____
   ____

For questions 8 – 13, please circle how likely you would be to use each resource.

Please fill in your suggestions in the box on the right for the resources you would like to use.

8. If **pamphlets** were available, how likely would you be to use them with your patients?
Please circle below.

Very unlikely Moderately likely Very likely

0 1 2 3 4 5 6 7 8 9 10

What information should be included in the pamphlet?
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………

9. If **flashcards** were available, how likely would you be to use them with your patients?
Please circle below.

Very unlikely Moderately likely Very likely

0 1 2 3 4 5 6 7 8 9 10

What HIV/AIDS or TB-related topics should the flashcards include?
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………

10. If **posters** were available, how likely would you be to use them with your patients?
Please circle below.

Very unlikely Moderately likely Very likely

0 1 2 3 4 5 6 7 8 9 10

What information should be included in the poster?

....

....

....

....

11. If a **translation app** were available, how likely would you be to use them with your patients?
Please circle below.

Very unlikely Moderately likely Very likely

0 1 2 3 4 5 6 7 8 9 10

What would be most important to you in an app like this?

....

....

....

....

12. If a healthcare-specific **language learning app** were available, how likely would you be to use them with your patients?
Please circle below.

Very unlikely Moderately likely Very likely

0 1 2 3 4 5 6 7 8 9 10

What would you want to learn on an app like this?

....

....

....

....

13. If informative **videos** in your patient's home language were available, how likely would you be to use them with your patients?
Please circle below.

Very unlikely Moderately likely Very likely

0 1 2 3 4 5 6 7 8 9 10

What HIV/AIDS and/or TB-related concepts would be most important to have videos for?

....

....

....

....

14. What else, if anything, do you think could help to make communication easier between you and your patients? ____

____

____

14. Is there anything else you'd like to add?

____

____

____

15. Further communication: Please tick all the boxes that apply.
☐ I am happy to be contacted if the researcher has any other questions.
☐ I would like to participate in an online group discussion via Zoom or WhatsApp call with other healthcare professionals to speak about the resources in more detail.
☐ I want to receive a copy of the research results.
☐ I do not want to receive any further communication about this project.

16. If you would like to receive further communication, please provide your email address or WhatsApp number. Your contact details will not be shared. ______________________________

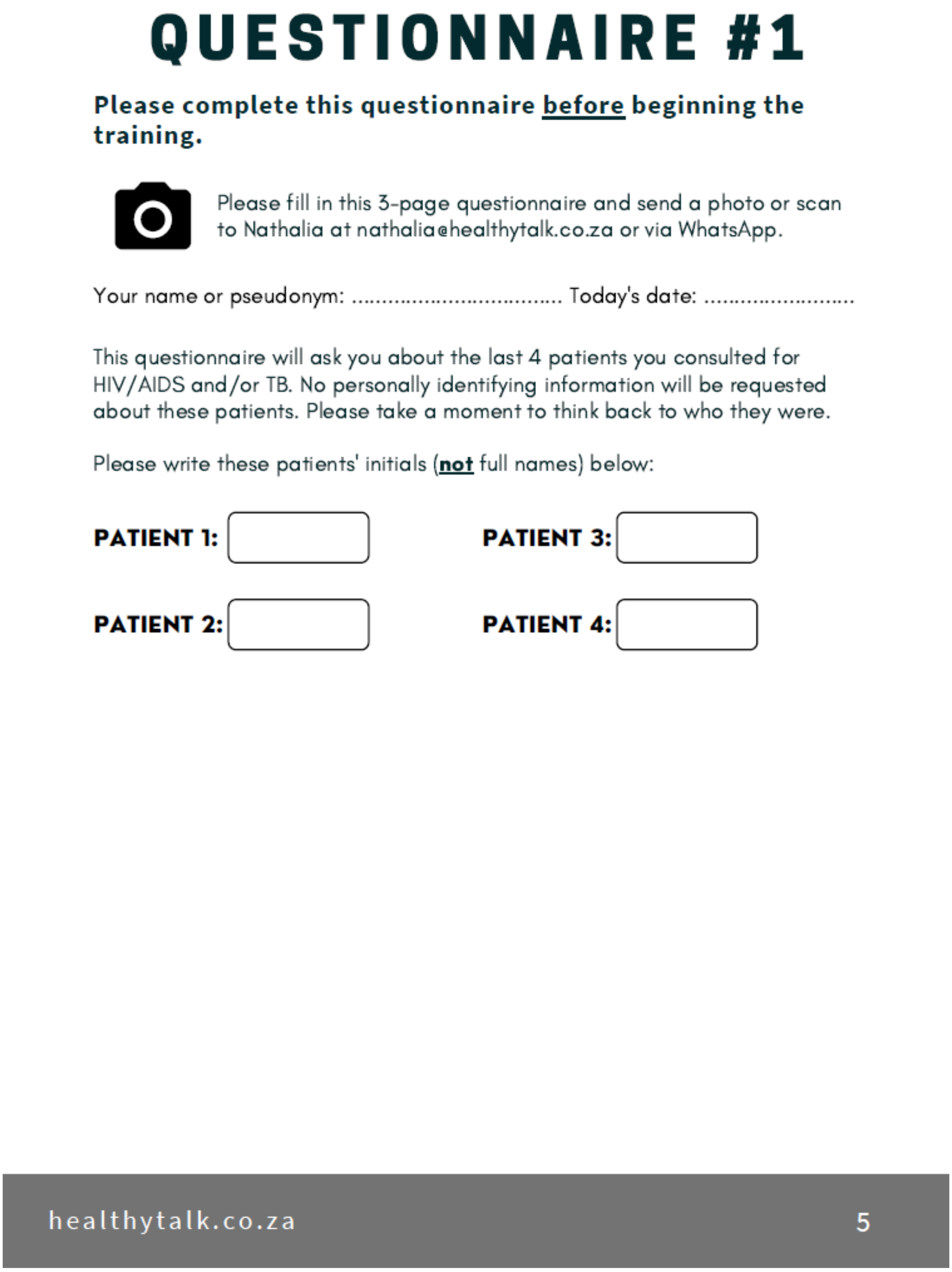
Appendix 15: Pilot feasibility focus group discussion schedule for feedback on proposed resources

1. Introductions, explanation of the study, consent.
2. General questions:
    a. What language(s) would you say most of your patients speak?
    b. Is there a need to work with an interpreter? If so, how regularly, and who interprets?
    c. Do you have any other resources to help with communication?
3. Presentation of resource preview pack, with explanations if video hasn't been watched, and pausing after paper-based slides and digital slides to ask:
    a. How likely would you be to use this resource?
    b. What should we keep in mind? Or any suggestions?
    c. What else (if anything) do you think could help make communication easier between you and your patients?
4. Suggestions for training?
5. Thank you and next steps of the study.

Appendix 16: Pilot feasibility T1 questionnaire

This questionnaire was used as T1 with the intervention group, and as T1-T3 with the control group.

The questionnaire was included in the *Healthy Talk* communication manual.



QUESTIONNAIRE #1

Please complete this questionnaire before beginning the training.

Please fill in this 3-page questionnaire and send a photo or scan to Nathalia at nathalia@healthytalk.co.za or via WhatsApp.

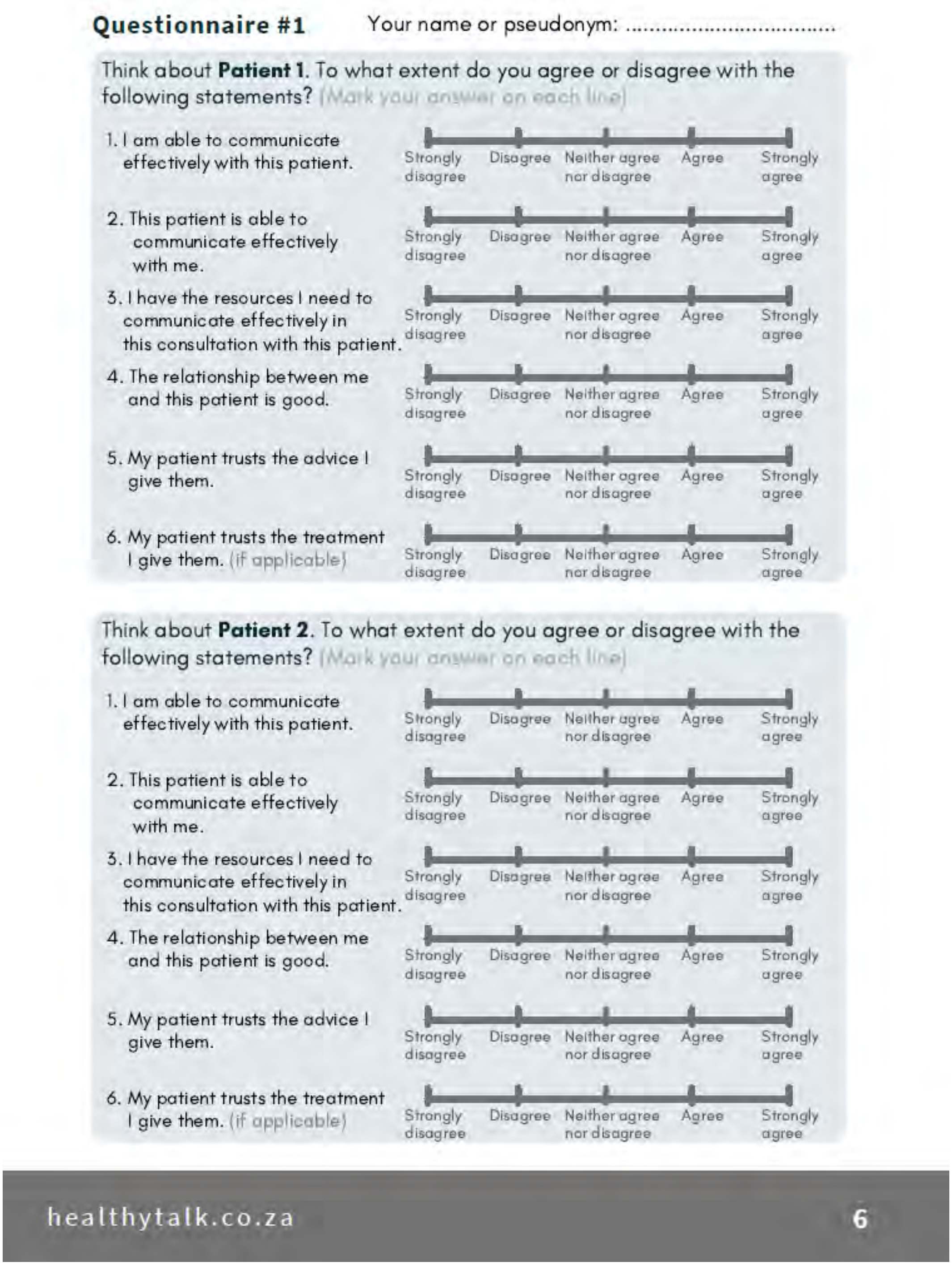
Your name or pseudonym: .... Today's date: ....

This questionnaire will ask you about the last 4 patients you consulted for HIV/AIDS and/or TB. No personally identifying information will be requested about these patients. Please take a moment to think back to who they were.

Please write these patients' initials (**not** full names) below:

PATIENT 1: ☐ **PATIENT 3:** ☐

PATIENT 2: ☐ **PATIENT 4:** ☐



Questionnaire #1 Your name or pseudonym: ....

Think about **Patient 1**. To what extent do you agree or disagree with the following statements? (Mark your answer on each line)

1. I am able to communicate effectively with this patient.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
2. This patient is able to communicate effectively with me.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
3. I have the resources I need to communicate effectively in this consultation with this patient.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
4. The relationship between me and this patient is good.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
5. My patient trusts the advice I give them.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
6. My patient trusts the treatment I give them. (if applicable)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

Think about **Patient 2**. To what extent do you agree or disagree with the following statements? (Mark your answer on each line)

1. I am able to communicate effectively with this patient.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
2. This patient is able to communicate effectively with me.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
3. I have the resources I need to communicate effectively in this consultation with this patient.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
4. The relationship between me and this patient is good.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
5. My patient trusts the advice I give them.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
6. My patient trusts the treatment I give them. (if applicable)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

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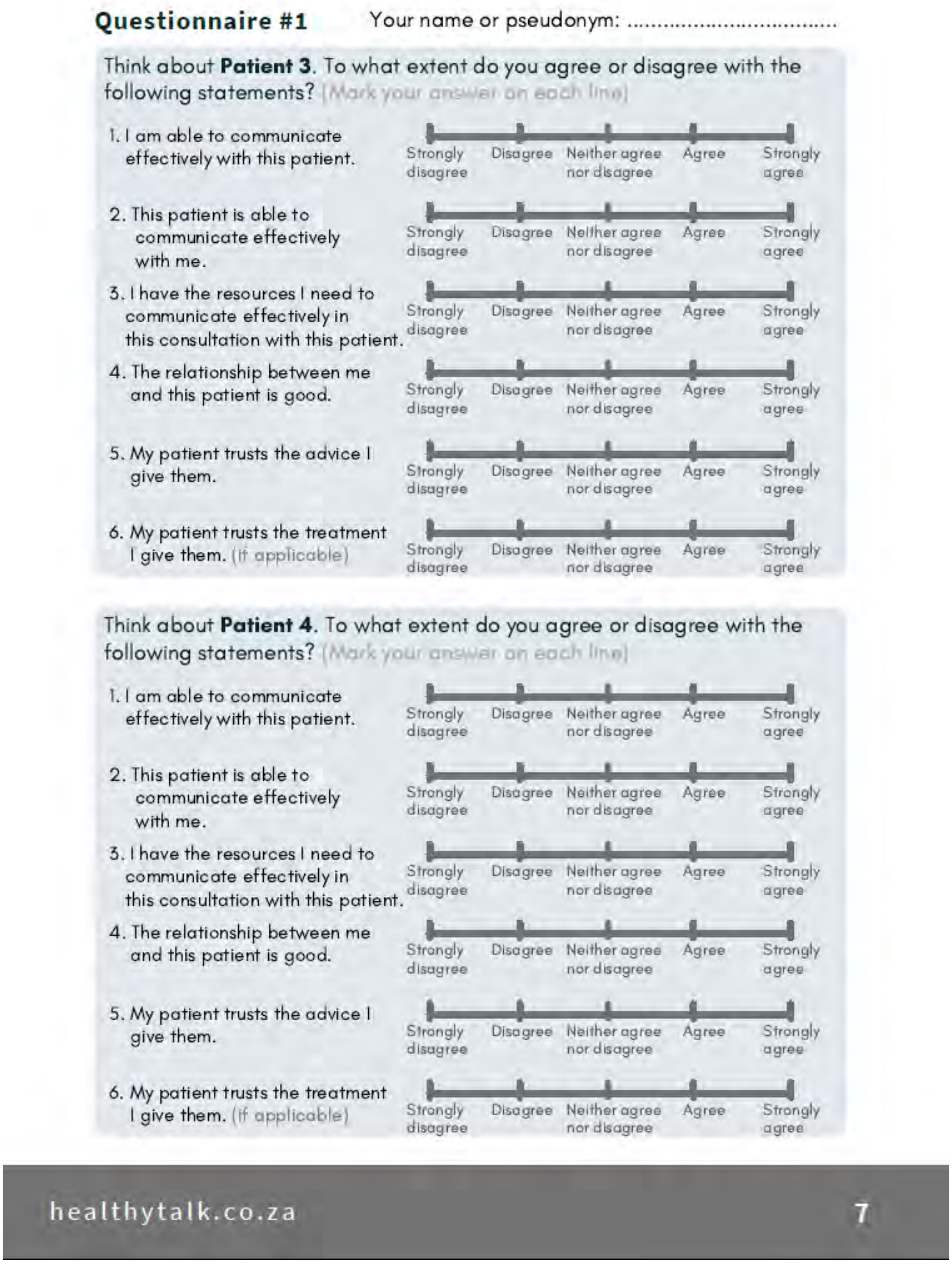

Questionnaire #1 Your name or pseudonym: ....

Think about **Patient 3**. To what extent do you agree or disagree with the following statements? (Mark your answer on each line)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. I am able to communicate effectively with this patient.					
2. This patient is able to communicate effectively with me.					
3. I have the resources I need to communicate effectively in this consultation with this patient.					
4. The relationship between me and this patient is good.					
5. My patient trusts the advice I give them.					
6. My patient trusts the treatment I give them. (If applicable)					

Think about **Patient 4**. To what extent do you agree or disagree with the following statements? (Mark your answer on each line)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. I am able to communicate effectively with this patient.					
2. This patient is able to communicate effectively with me.					
3. I have the resources I need to communicate effectively in this consultation with this patient.					
4. The relationship between me and this patient is good.					
5. My patient trusts the advice I give them.					
6. My patient trusts the treatment I give them. (If applicable)					

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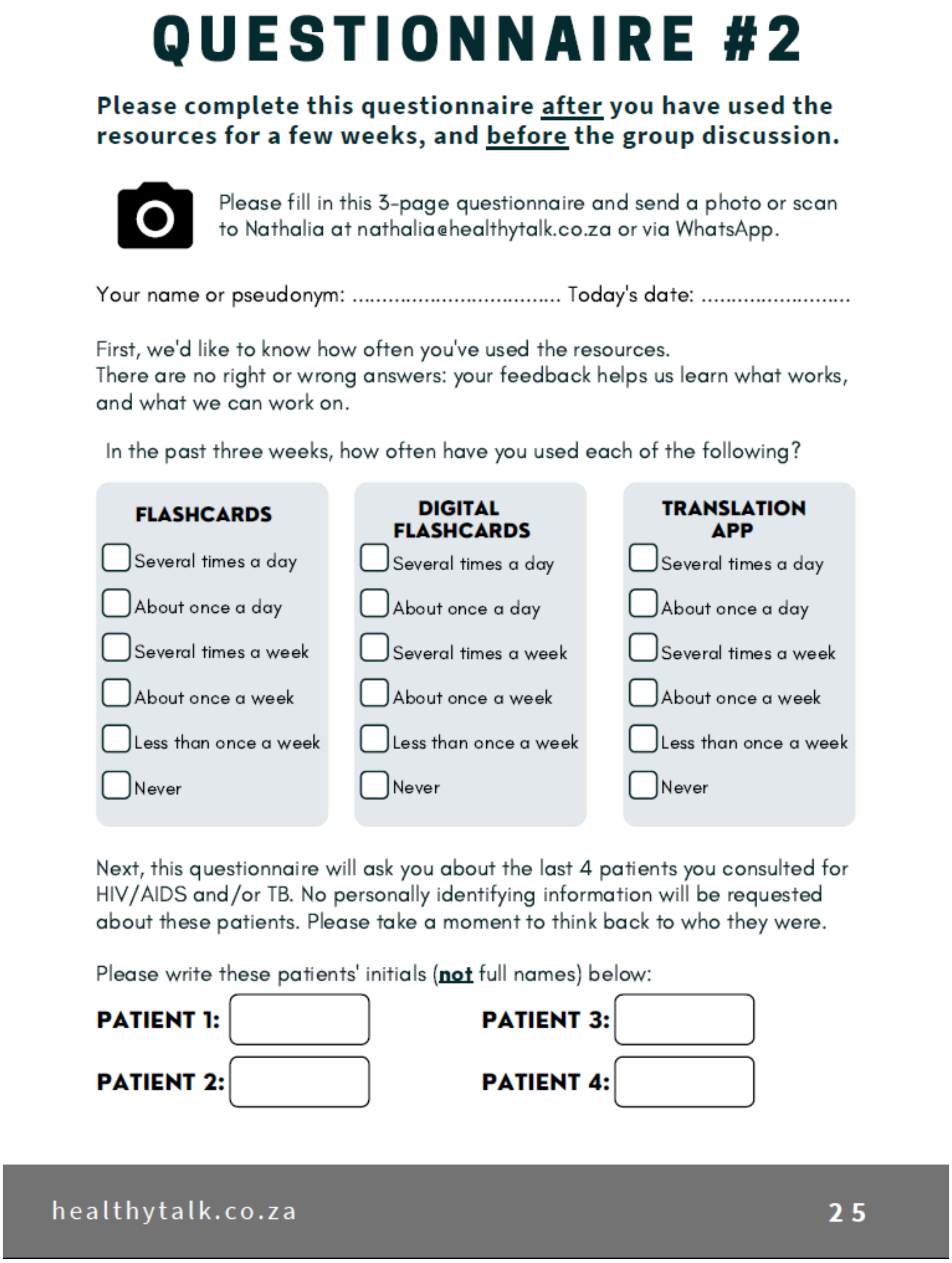
Appendix 17: Pilot feasibility T2-T3 questionnaire

This questionnaire was used as T2 and T3 questionnaire with the intervention group.

The questionnaire was included in the *Healthy Talk* communication manual.



QUESTIONNAIRE #2

Please complete this questionnaire after you have used the resources for a few weeks, and before the group discussion.

Please fill in this 3-page questionnaire and send a photo or scan to Nathalia at nathalia@healthytalk.co.za or via WhatsApp.

Your name or pseudonym: .... Today's date: ....

First, we'd like to know how often you've used the resources.
There are no right or wrong answers: your feedback helps us learn what works, and what we can work on.

In the past three weeks, how often have you used each of the following?

FLASHCARDS	DIGITAL FLASHCARDS	TRANSLATION APP
☐ Several times a day	☐ Several times a day	☐ Several times a day
☐ About once a day	☐ About once a day	☐ About once a day
☐ Several times a week	☐ Several times a week	☐ Several times a week
☐ About once a week	☐ About once a week	☐ About once a week
☐ Less than once a week	☐ Less than once a week	☐ Less than once a week
☐ Never	☐ Never	☐ Never

Next, this questionnaire will ask you about the last 4 patients you consulted for HIV/AIDS and/or TB. No personally identifying information will be requested about these patients. Please take a moment to think back to who they were.

Please write these patients' initials (**not** full names) below:

PATIENT 1: ☐
PATIENT 2: ☐
PATIENT 3: ☐
PATIENT 4: ☐

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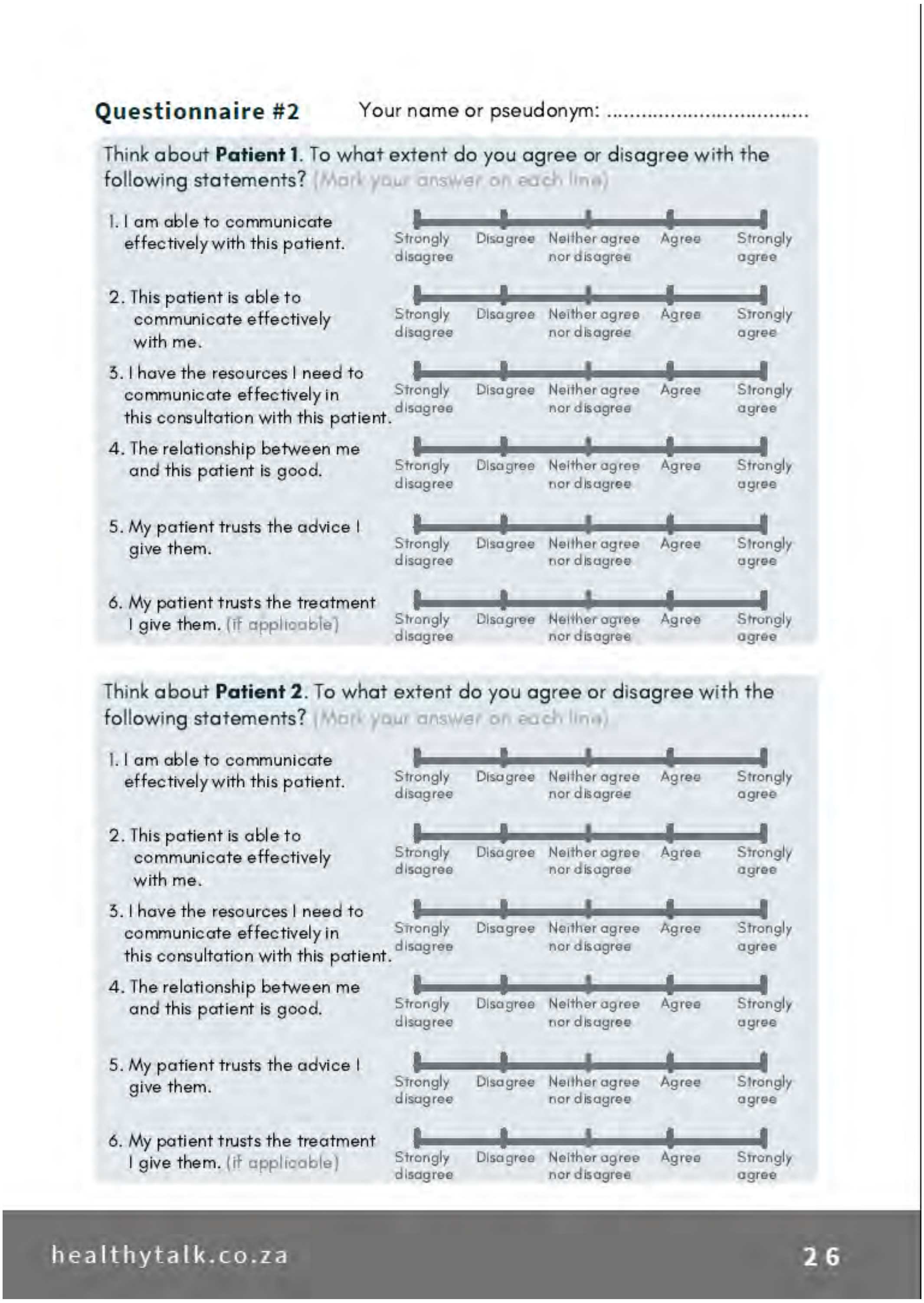


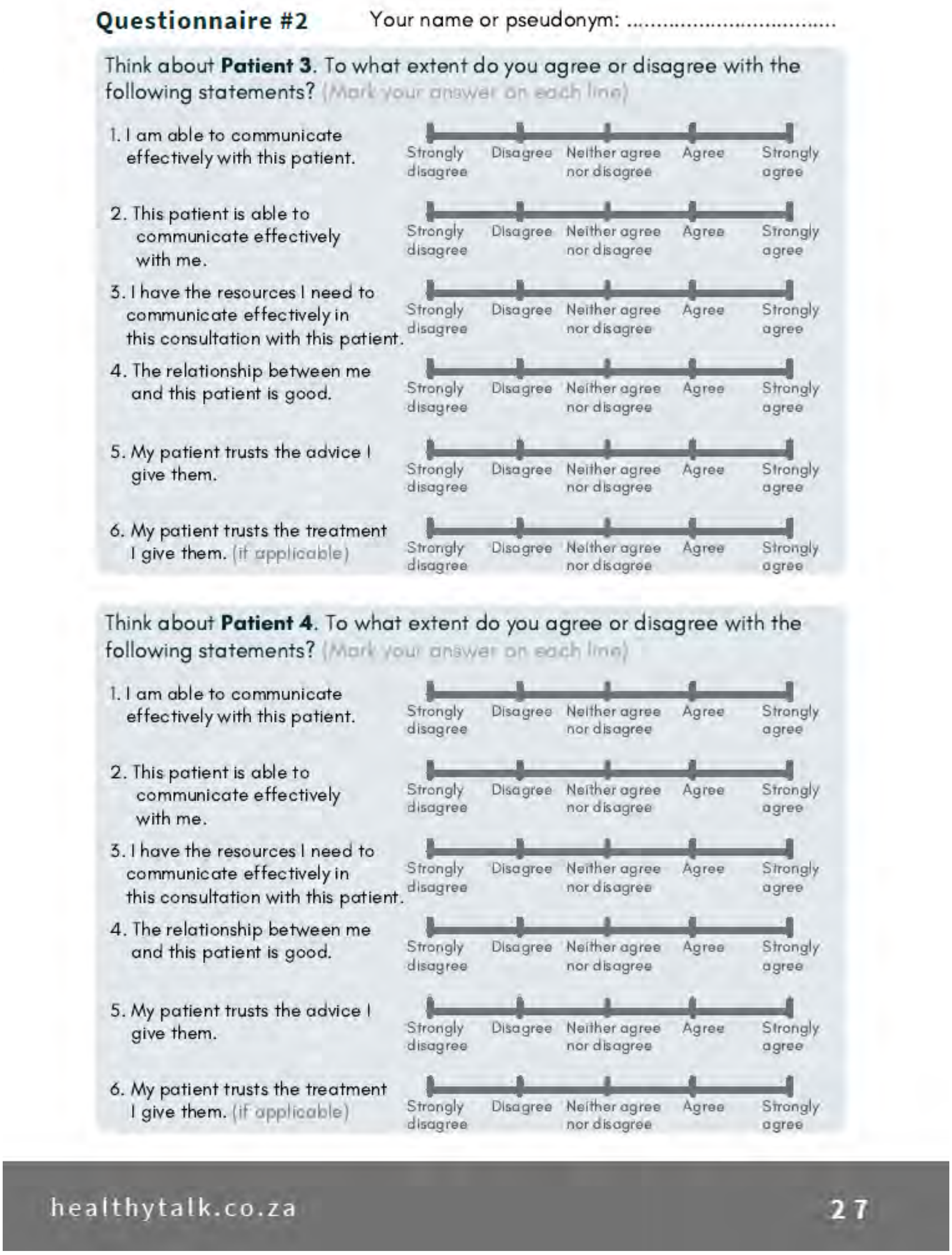
Questionnaire #2 Your name or pseudonym: ....

Think about **Patient 1**. To what extent do you agree or disagree with the following statements? (Mark your answer on each line)

1. I am able to communicate effectively with this patient.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
2. This patient is able to communicate effectively with me.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
3. I have the resources I need to communicate effectively in this consultation with this patient.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
4. The relationship between me and this patient is good.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
5. My patient trusts the advice I give them.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
6. My patient trusts the treatment I give them. (if applicable)
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree

Think about **Patient 2**. To what extent do you agree or disagree with the following statements? (Mark your answer on each line)

1. I am able to communicate effectively with this patient.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
2. This patient is able to communicate effectively with me.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
3. I have the resources I need to communicate effectively in this consultation with this patient.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
4. The relationship between me and this patient is good.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
5. My patient trusts the advice I give them.
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree
6. My patient trusts the treatment I give them. (if applicable)
   Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree



Questionnaire #2 Your name or pseudonym: ....

Think about **Patient 3**. To what extent do you agree or disagree with the following statements? (Mark your answer on each line)

1. I am able to communicate effectively with this patient.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
2. This patient is able to communicate effectively with me.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
3. I have the resources I need to communicate effectively in this consultation with this patient.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
4. The relationship between me and this patient is good.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
5. My patient trusts the advice I give them.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
6. My patient trusts the treatment I give them. (if applicable)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

Think about **Patient 4**. To what extent do you agree or disagree with the following statements? (Mark your answer on each line)

1. I am able to communicate effectively with this patient.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
2. This patient is able to communicate effectively with me.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
3. I have the resources I need to communicate effectively in this consultation with this patient.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
4. The relationship between me and this patient is good.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
5. My patient trusts the advice I give them.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
6. My patient trusts the treatment I give them. (if applicable)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

Appendix 18: Pilot feasibility follow-up interview schedule

1. Introduction to the interview and confirmation of continued informed consent.
2. Feasibility of the study:
    a. Why did you choose to participate in the study?
    b. What facilitated your participation in the study (or what made it easy to participate in the study)?
    c. What barriers did you experience (or what made it difficult to participate in the study)?
3. Feasibility of the resources:
    a. On your questionnaires you said you used [specific resource added] [specified regularity added]. Can you tell me a bit more about how you used it?
    b. What effect do you think this resource had on your communication with your patient?
    c. What effect do you think this resource had on your relationship with your patient?
    d. What do you think was the most important or helpful thing about this resource?
    e. What do you think should be changed about this resource?
4. Thank you and next steps of the research.

Resources

Appendix 19: Resource preview pack (video)

The resource preview pack video can be accessed here:

<http://bit.ly/HealthyTalkPresentation1>

Appendix 20: Resource preview pack (presentation slides)

The resource preview pack presentation slides can be accessed here:

<https://drive.google.com/file/d/1llzD6_yAXtpoEawuVIqxSxgTgRm9ampd/view?usp=sharing>

Appendix 21: *Healthy Talk* communication manual

The *Healthy Talk* communication manual can be accessed here:

<https://drive.google.com/file/d/1DX7GvaWI-Orujv9fSWzo0S84cblgmlgI/view?usp=sharing>

Appendix 22: *Healthy Talk* flashcards

The *Healthy Talk* flashcards can be accessed in the following folder:

<https://drive.google.com/drive/folders/1nC5EoQ4OZsraN3o6Ezs9nFaYzIEpRVOF?usp=sharing>

Appendix 23: *Healthy Talk* training videos

The *Healthy Talk* training videos (to accompany the communication manual) can be accessed in the following folder:

<https://drive.google.com/drive/folders/1gxJd6MG3JJfYZIsgbGpcFvultg9gVfuU?usp=sharing>

Other appendices

Appendix 24: CONSORT guidelines

Checklist from Eldridge et al. (2016b: 355).

CONSORT 2010 checklist of information to include when reporting a pilot or feasibility trial*

Section/Topic	Item No	Checklist item	Reported on page No
Title and abstract			
	1a	Identification as a pilot or feasibility randomised trial in the title	152
	1b	Structured summary of pilot trial design, methods, results, and conclusions (for specific guidance see CONSORT abstract extension for pilot trials)	152-153
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale for future definitive trial, and reasons for randomised pilot trial	167
	2b	Specific objectives or research questions for pilot trial	153
Methods			
Trial design	3a	Description of pilot trial design (such as parallel, factorial) including allocation ratio	153-154
	3b	Important changes to methods after pilot trial commencement (such as eligibility criteria), with reasons	163-165
Participants	4a	Eligibility criteria for participants	161-162
	4b	Settings and locations where the data were collected	159-161
	4c	How participants were identified and consented	161; 166
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	153-158

Outcomes	6a	Completely defined prespecified assessments or measurements to address each pilot trial objective specified in 2b, including how and when they were assessed	180-181
	6b	Any changes to pilot trial assessments or measurements after the pilot trial commenced, with reasons	N/A
	6c	If applicable, prespecified criteria used to judge whether, or how, to proceed with future definitive trial	N/A
Sample size	7a	Rationale for numbers in the pilot trial	104-105
	7b	When applicable, explanation of any interim analyses and stopping guidelines	N/A
Randomisation:			
Sequence generation	8a	Method used to generate the random allocation sequence	154
	8b	Type of randomisation(s); details of any restriction (such as blocking and block size)	154
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	154
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	154
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	N/A
	11b	If relevant, description of the similarity of interventions	N/A
Statistical methods	12	Methods used to address each pilot trial objective whether qualitative or quantitative	72
Results			
Participant flow (a diagram is	13a	For each group, the numbers of participants who were approached and/or assessed for eligibility, randomly assigned, received intended treatment, and were assessed for each objective	163-165

strongly recommended)	13b	For each group, losses and exclusions after randomisation, together with reasons	163-165
Recruitment	14a	Dates defining the periods of recruitment and follow-up	97
	14b	Why the pilot trial ended or was stopped	N/A
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	195
Numbers analysed	16	For each objective, number of participants (denominator) included in each analysis. If relevant, these numbers should be by randomised group	181
Outcomes and estimation	17	For each objective, results including expressions of uncertainty (such as 95% confidence interval) for any estimates. If relevant, these results should be by randomised group	196-200
Ancillary analyses	18	Results of any other analyses performed that could be used to inform the future definitive trial	180-215
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	N/A
	19a	If relevant, other important unintended consequences	215-217
Discussion			
Limitations	20	Pilot trial limitations, addressing sources of potential bias and remaining uncertainty about feasibility	224
Generalisability	21	Generalisability (applicability) of pilot trial methods and findings to future definitive trial and other studies	223-224
Interpretation	22	Interpretation consistent with pilot trial objectives and findings, balancing potential benefits and harms, and considering other relevant evidence	215-217
	22a	Implications for progression from pilot to future definitive trial, including any proposed amendments	217-218
Other information			
Registration	23	Registration number for pilot trial and name of trial registry	242
Protocol	24	Where the pilot trial protocol can be accessed, if available	242

Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	iv
	26	Ethical approval or approval by research review committee, confirmed with reference number	239-241

List of tables, figures and equations