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# ICT4D & HIV/AIDS:

An exploration of mHealth for HIV/AIDS in  
South Africa

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award of the degree of:*

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## Plagiarism Declaration

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in this dissertation from the work or works of other people has been attributed, cited, and referenced.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

University of Cape Town

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## **Abstract**

*This study contextualises the HIV/AIDS pandemic in South Africa within the field of Information Communication Technology for Development (ICT4D). Specifically, it outlines the strengths and weaknesses of current Mobile Health (mHealth) programmes and offers solutions to bolster their effectiveness. For the purposes of this study, I engaged in action research in that I contributed towards the creation of an SMS based mHealth for HIV/AIDS programme. The creation of the programme's content was heavily informed by the Health Belief Model. The programme was then offered at HIV testing clinics to those that had undergone an HIV test. Individuals were offered the choice between SMSs aimed at those who had tested positive and SMSs aimed at those who had tested negative. Midway through the programme, I conducted participant interviews and reviewed key documents as part of an assessment. Interviews with HIV/AIDS testing counsellors were later conducted as well. This information was used in order to assess the current success of the programme. The data revealed that a crucial component of the programme's success was the 'buy-in' from HIV/AIDS testing counsellors and nurses. To ensure buy-in, the nurses and counsellors whose patients are the programme should receive in depth training and explanation of the programme's purpose and functions. Furthermore, the emphasis put on sex and HIV in the SMSs for HIV- individuals should be re-evaluated. I recommend that this set of SMSs should rather have a greater focus on general health promotion. Finally, in response to the overwhelming feedback on the matter, this mHealth programme should be extended to six months rather than three. Although the scope of this study was limited to one mHealth programme that was piloted in the Overberg region of the Western Cape and later offered at HIV/AIDS testing centres in the Port Elizabeth area of the Eastern Cape, the findings and recommendations from this study can be used to inform further research and evaluation as well as the creation of other SMS based mHealth programmes.*

## Abbreviations

HBM	Health Belief Model
ICT	Information Communication Technology
ICT4D	Information Communication Technology for Development
mHealth	Mobile Health
MMS	Multimedia Message Service
PCM	Please Call Me
PEPFAR	President's Emergency Plan for AIDS Relief
SCT	Social Cognitive Theory
SMS	Short Message Service
TPB	Theory of Planned Behaviour
UN	United Nations
UNAIDS	The Joint United Nations Programme for HIV/AIDS
UNGASS	United Nations General Assembly Special Session

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# Chapter 1. Introduction

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## 1.1 Background of the Problem

South Africa is a country heavily affected by the HIV pandemic. Although HIV prevalence has begun to plateau around 30% in antenatal care patients, the absolute number of people living with HIV/AIDS increases at about 100,000 additional people each year (Health and Development Africa, 2012: 12). The increase in the number of HIV infections each year is indication that new and innovative approaches to the crisis must be explored. According to a United Nations Programme on HIV/AIDS [UNAIDS] report done in 2009, approximately 17.8% of South Africans between the ages of 15 and 49 years are HIV positive. In total, approximately 5.6 million South Africans are living with HIV, and one third of those people are between the ages of 15 and 25 (Forman, 2003: 4). A further 1.3 million children between the ages of 0 and 17 years have been orphaned due to HIV/AIDS. These figures are staggering; it is almost no surprise that South Africa has the largest population of HIV positive people, 5.7 million, in the entire world (UNAIDS, 2009: 27).

Despite the large amount of funding allotted to HIV prevention and education initiatives, the number of infections continues to rise. The South African government spent an approximated 8.4 billion rand on HIV and AIDS in 2010 alone<sup>1</sup>. In addition national expenditure, South Africa also receives funding through international donors. The United States President's Emergency Plan For AIDS Relief [PEPFAR], contributed 2 billion dollars (approximately 15 billion rand), between 2004 and 2009 for various prevention initiatives (PEPFAR, 2011). Yet in that same time frame, the percentage of people with HIV/AIDS in South Africa rose from 11% in 2004 (Dorington et al, 2004: 9) to 16.9% in 2009 (UNAIDS, 2009). With a rapidly rising number of HIV infections, researchers are pressed to not only understand why previous treatment initiatives have failed to

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<sup>1</sup> <http://www.southafrica.info/business/economy/policies/hiv-170210.htm>

stop this increase despite the extensive funding, but also to create sustainable, effective responses to the disease.

## **1.2 Collaborative Responses**

Diseases like HIV/AIDS are inextricably bound to other social factors such as poverty, unemployment, education, and welfare. In turn, current responses to the HIV/AIDS pandemic are becoming more interdisciplinary. One increasingly prevalent example of such a response is the concept of “mobile health” or mHealth.

mHealth is a subset of the larger Information Communication Technology for Development [ICT4D] field. ICT4D attempts to merge Information Communication Technology [ICT], such as radios, television, cell phones, and internet, with the field of development (Heeks, 2008). ICT has completely changed the way many people receive and transfer information; recent studies have shown its importance, crediting it as a key source in human development (Forman, 2003: 13). This flow of information is predicted to have a significant effect on education, health, development, and politics (ibid). In response to governments’ limitations of knowledge and communication sources during the recent ‘Arab Spring,’ the United Nations [UN] Special Rapporteur Frank La Rue pronounced internet access to be a human right; in doing so, he placed it at the level of importance of other human rights such as the freedom of speech (Phillips, 2011). He was speaking specifically about limitation; universal internet access is, at this point, an unfeasible goal. However, UN recognition brings attention to the importance and relevance of ICT in today’s political and social landscape.

Within the sphere of ICT4D, mHealth has emerged as the most feasible and relevant option for Sub-Saharan Africa. Currently, it is estimated that four out of 10 people in this region are cell phone owners (Porter, et al: 2012:145). In South Africa there are 45 million cell phone

subscriptions (Makoe, 2010:251). Cell phones possess several features which cater to the needs of transmitting information for sensitive diseases such as HIV/AIDS. Cell phones are more private than traditional broadcast media such as TV or radio which allows users to feel more comfortable using them to read and even store personal information. As opposed to one-way communication modes like television or radio, cell phones have the capacity for two-way interaction which means there is a possibility for richer communication. While one-way communication methods specialise in 'broadcasting' information, cell phones have the ability to transmit user-specific, personalised information. They can be accessed from remote areas, and through them, informational messages can be updated quickly and easily. These aspects make mobile technology an interesting and important potential tool for the South African communities that are heavily affected by HIV/AIDS. As Pop-Eleches (2011:1) states, "mobile phones have been shown to improve chronic disease management in developed countries and have been proposed as a potential strategy to support adherence in developing countries." In a place with such a wide spread cell phone culture, mobile technology has the potential to play a monumental role in the fight against HIV and AIDS.

### **1.3 Purpose of the Study**

The purpose of this study is to contribute to the growing body of knowledge supporting innovative ways of tackling the HIV crisis, specifically in the mHealth sector. My research attempts to add knowledge to the merger of development and ICT by determining how and to what degree of success mobile telephones are being used to provide support and knowledge dissemination for people affected by HIV/AIDS in South Africa.

As previously mentioned, billions of dollars are directed towards the pandemic each year and yet the rate of HIV infections continues to increase (Health and Development Africa, 2012: 12). With

the rise of the availability and use of cell phones in Sub-Saharan Africa, it is an opportune moment to link the two phenomena in order to combat the epidemic. ICT has proven its power and potential to transmit knowledge and increase communication in many different settings around the world (Okpaku, 2003, Heeks 2, 2010); this leads me to question how it is being used to communicate health information and provide support for South Africans affected by HIV/AIDS and to look at ways of improving its efficacy. This thesis will attempt to answer the following questions:

1. How is mHealth being used to address HIV/AIDS in South Africa?
2. Can mHealth programmes be successful in supporting the treatment and prevention of HIV/AIDS?
3. How was the “Just Tested for HIV” programme received by the participants?

In order to answer these questions, I chose a qualitative approach by engaging in action research. After reviewing the body of ICT4D and mHealth literature, I worked closely with a mHealth organisation to develop a short message service [SMS] based, HIV/AIDS support and knowledge programme. Following its creation, I conducted a midway assessment, interviewed key stakeholders, and reviewed key documents to evaluate the success of the programme.

## **1.4 Background of the Study**

In order to address the state of mHealth in South Africa, I approached a well-known mHealth organisation based in Cape Town called Cell Life. Cell Life allowed me to work in conjunction with them in creating a free SMS based programme which supports the treatment and prevention of HIV/AIDS. We closely followed a behavioural health model during the creation phase of the programme. The programme was then piloted to the public in the Overberg region of the Western Cape via a mobile testing centre. After piloting the programme, I conducted in-depth interviews

with programme participants and unstructured interviews with HIV testing counsellors. I was also given access to Cell Life documents regarding programme statistics to further enhance my data collection. Grounded theory methodology was used to analyse the interviews and those results were balanced with analysis of the SMS based programme documents in order to answer my research questions.

## **1.5 Thesis Outline**

Following this introduction, chapter two contains a literature review which combines the schools of development and mobile technology. It also unpacks the theories that were used in the creation and evaluation of the SMS programme. Chapter three focuses on the case study at hand. It gives a background of the organisations with which I collaborated for this study and unpacks the concept of action research. It also explains the process of the creation of the SMS based programme that was developed. Chapter four focuses on the methodology, including an explanation of the case study methods. It also highlights the research methods used as well as the methods employed for data analysis. Chapter five discusses and analyses the findings of the research. It addresses the theory driving the analysis as well as the process of analysis in regards to the interviews and documents. In it, the main themes extracted from the interviews are discussed at length. The thesis will conclude with chapter five which consists of recommendations and a conclusion.

# Chapter 2. Literature Review

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In this chapter I contextualise HIV/AIDS and its logical connection to mobile phones within the history of the field of development. I provide examples of ICT4D projects and mHealth programmes that have already been developed and implemented in Africa. Furthermore, I will explore the health behaviour model that is used further in the thesis.

## 2.1 The Challenge of Development

Major health issues such as the HIV/AIDS epidemic are inextricably bound to the larger matter that is development. However, one of the major challenges of development is simply defining it. The concept can be described as the attainment of various national economic and social goals; but under this definition, two different developmental trajectories emerged. One road follows a more Northern Hemisphere for Northern Hemisphere agenda. Development as such became an international priority after the end of World War Two which left much of Europe in ruins. It was to the Northern Hemisphere's advantage to repair itself and was successful in doing so. Development continued to be on the international agenda through the next few decades as the European states began abandoning their colonial presence on the African continent. It is at this point that a second notion of development materialised because the power imbalance between the Northern and Southern hemisphere which characterised colonialism left a legacy of challenges that 'development' not only sought to remedy but also often embodied (Ashraf, 2008: 13).

Various initiatives aided in the rebuilding of Europe but the massive inequalities visible in post-colonial Africa proved to be a bigger challenge. The idea of 'developing' these nations in order for them to more closely reflect life in the Northern Hemisphere became the standard approach to addressing post-colonial Africa (Escobar, 1995). At the time, development initiatives fell into one of two distinct approaches. Economic development often uses GDP as an indicator for standard

living and a numerical method for measuring development. The economic approach to development has been criticised for not fully representing the lives and realities of individuals. In cases where nations have both very wealthy and very poor people, such as South Africa and Brazil, the GDP would show a skewed level of national development. The social approach (Midgley, 1995) to development, however, employs indicators that focus on the human perspective. This often includes health standards, education levels, employment opportunities, life expectancy, and so on (Ashraf, 2008: 14). The approaches were almost completely mutually exclusive and the distinction between the two set the tone for the development initiatives of the time and for years to come (ibid: 16).

Development through the 1980s continually failed to achieve its intended results. The focus on economic development, the popular approach of the time, had not managed to reverse the huge disparity between the Global North and the Global South (Escobar, 1995). Economic indicators alone were unable to paint a full picture of the human experience; the focus on the economy was doing little to change the lives of an average citizen in the nations that were seen as underdeveloped. As a response to the failure of economic indicators, the idea of human development became prominent in the 1980s (ibid: 16). One of the most significant contributors to human development theory is development theorist and economist, Amartya Sen.

### ***2.1.1 Capabilities approach***

Although Sen has been criticised for placing too much emphasis on individual freedoms as opposed to social preferences (Evans, 2002), Sen has contributed to development rhetoric in key ways. Firstly, despite being an economist, he is a major critic of the development of old which, he argues, conflates and confuses the idea of well-being with opulence and utility (Clark, 2005). Secondly, he put forth a new development framework in which well-being equates to human capabilities or freedoms which people have and value (Clark, 2005).

Capabilities approach disputes the GDP as an adequate indicator for development and instead emphasises these human capabilities, or freedoms, as the most relevant way to gauge the success of a nation's development. This freedom that Sen emphasizes is the wherewithal or the capacity to make personal choices (Walker, 2008). Under the capabilities approach, having freedoms allows people to attain various functionings which Sen defines as "beings and doings" (Sen 1992). Although achieving functionings can be considered positive (for example being a healthy individual or doing well in business), it is not so much the achieved functionings that matter as much as having the freedoms that one needs to realise them. In this vein, development is actually the freedom of choice, and it is up to the individual to decide how to engage with their freedoms (Walker, 2008).

Sen (1999, xi-xii) asserts that there is "a deep complementarity between individual agency and social arrangements...[and] the force of social influences on the extent and reach of individual freedom." The complimentary relationship between these forces can be seen clearly in the South African context; many experience a lack of personal agency which directly results in unequal social arrangements, a situation which was very much dictated social influences, such as the country's political history. The relationship of these phenomena has resulted in the limitation of freedoms and functionings for many of the nation's citizens. According to Sen, ensuring that people have equal and proper amounts of functionings is cornerstone to reversing the abject effects of the political and social failings of the past.

Sen acknowledges that poverty cannot be broken into individual parts; education is related to economics which is related to health and so on; they are all related functionings. This notion was central to the creation of the Human Development Index, the composite statistic that the United Nations eventually developed to measure the human development and standard of living in each

country<sup>2</sup>. Such a concept speaks to the reality and the necessity of new interdisciplinary approaches and marriages of previously unrelated ideas to better address development's many challenges.

In 2000, the United Nations Programme on HIV/AIDS produced a report in which it detailed how the AIDS virus fit into the development context (Collins and Rau, 2000). Drawing upon Sen's concept of related and intertwined functionings, the report states that addressing HIV/AIDS solely from a public health perspective is inadequate and that other social factors must be addressed. The authors argue that the response to the HIV/AIDS pandemic, like all other factors of poverty, requires a holistic approach to achieve progress (ibid: 39).

In a world that is rapidly globalising, issues, strategies, and information flow more freely across political lines due to the ease of transmission that various ICT has provided. As the world becomes fluid and interconnected, so should our approach to development. One of the newest synergies between different schools of thought has resulted in a new school of development called Information and Communication Technologies for Development or, in its shorthand form, ICT4D (Ashraf, 2008).

## **2.2 ICT4D**

Information Communication Technology, or ICT, was originally used for the development of corporations and the private sector, a practice which began in the early 1980s. Almost immediately, its value, in terms of generating wealth, was recognised. In the 1990s widespread use of ICT became a personal luxury with the explosion of the internet and its massive growth in use. Its power was not unnoticed by government and development agencies. When the UN put forth a list of Millennium Development Goals in 2000, it was inevitably paired with the power

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<sup>2</sup> [www.hdr.undp.org/en/humandevdevelopment](http://www.hdr.undp.org/en/humandevdevelopment)

and potential of the internet and ICTs. The merger of the two phenomena resulted in the creation of Information and Communication Technologies for human development (Heeks, 2008: 27).

The power and scope of ICT on a worldwide scale resulted in the idea of ICT4D, an arguably positive outcome. However, the massive expansion of information flow and wealth were advantages that disproportionately benefited the developed world. Therefore, while the growth of ICTs provided inspiration for a new development approach, this expansion also created another sphere in which the developed world far outpaced the developing one. The unequal distribution of ICTs is called the digital divide (Forman, 2003: 14).

### ***2.2.1 The Digital Divide***

It is difficult to fully comprehend the potential effects of a widening digital divide. Beyond economic implications, information regarding health, education, shelter, employment and so on is also increasingly unavailable to the “information poor” as digital distribution of the information becomes more popular. As the former Secretary General of the UN stated:

The new information and communication technologies are among the driving forces of globalisation. They are bringing people together, and bringing decision makers unprecedented new tools for development. At the same time, however, the gap between information ‘haves’ and ‘have-nots’ is widening, and there is a real danger that the world’s poor will be excluded from the emerging knowledge based global economy (Annan, 1999: 1).

The consequences of the digital divide could be that one portion of the world far outpaces the other in yet another important matter.

Ashraf (2008) suggests that the concept of the digital divide is a multi-faceted phenomenon that incorporates two different aspects of division. The first divide is on a global scale; the world is now separated into those that have access to the internet and those who do not. The second divide is social in nature. There is an ever-widening gap between those that are information rich and those that are information poor (ibid: 12).

In response to the digital divide, development initiatives were initially focused on providing internet access to regions without it; the provision of digital infrastructure such as computers became a common remedy. This approach was inspired by the state of the developed world where the internet is the driving force behind digital innovation (Bloome, 2002). Despite good intentions, this approach not only lacks scalability but also fails to take into consideration the idea of digital literacy. These early ICT4D initiatives emphasised the infrastructural side of solving the digital divide as opposed to the human aspect. In this regard, the initiatives did not address the capacity of communities to access ICT infrastructure. To avoid mistakes of the past, the digital divide should be addressed in terms of “the dimensions of societal concerns, including increasing people’s opportunities, developing appropriate content and people’s capacities to use ICT, especially in developing countries” (Ashraf, 2008: 13). Ashraf (2, 2008: 1) suggests that instead of this sort of “top down” development found in initiatives which focus on infrastructure, studies ought to consider the impact of ICT4D at the community and individual level to prevent further failure.

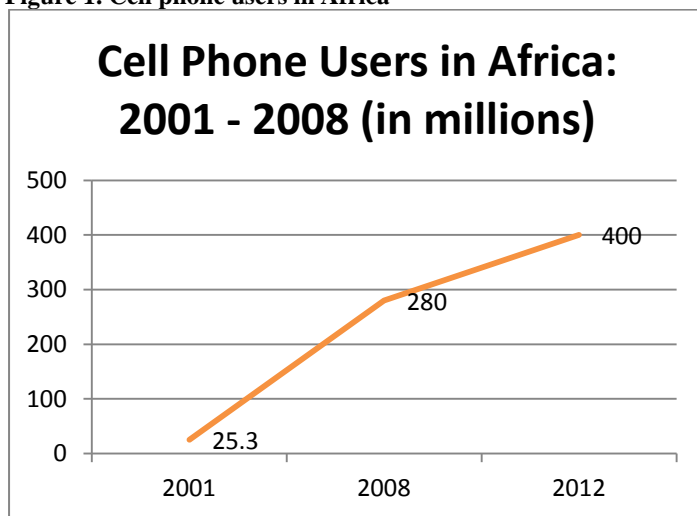
It is therefore essential for ICT4D projects to take into consideration how a community could use ICTs in their daily lives in a sustainable manner. With one in four people accessing radio, it is the most widely used and therefore most integrated, albeit simple, form of ICT on the African continent (Forman, 2003: 15). However, radio can only be used for mass communication and does not have the capacity for user interaction. Cell phones, another popular ICT device on the

African continent, with their wide spread use and ability for interaction make for an interesting point to investigate sustainable ICT4D projects.

### 2.2.2 Cell Phones in Sub-Saharan Africa

The very first call made on a cell phone in Sub-Saharan Africa was in 1987 in what was known then as Zaire (the Democratic Republic of the Congo now). “Market liberalization in a few key countries in the late 1990s and early 2000s contributed to the rapid growth in mobile phone users” (Etzo & Collender, 2010: 2). The use and scope of mobile phones in Sub-Saharan Africa has continued to expand and has done so dramatically over the past five years.

Figure 1. Cell phone users in Africa



Porter et al, 2012

In 2001, 25.3 million people were cell phone users. In 2008, that number had increased to 280 million. At the present moment an estimated 40 percent of the approximately 1 billion people living on the African continent have cell phones (Porter et al, 2012). In much of Sub-Saharan Africa the use of cell phones is now far more prevalent than that of landlines (Kaplan, 2006) and in South Africa specifically, 45 million people out of a population of 50 million subscribe to cell phone services (Makoe, 2010).

It has been found that, especially in terms of the youth, mobile phones are becoming an everyday part of life for many people, regardless of socio economic status (Porter et al, 2012). The increasingly high demand for cell phones has had positive economic and social results. Competition between cell phone coverage providers has produced many pro-poor incentives such as “prepaid airtime in low denominations, free off peak minutes, and free ‘please call me’ SMS” (ibid: 5). The ‘please call me’ SMS is a widely used service in which users can send a free SMS to anyone, requesting that that person who presumably can afford to make the call, phone them back. Individuals have also used the upsurge to their own economic benefit; for example, in South Africa there are many locally run ‘spaza shops’ whose income is largely dependent on the sale of cell phone airtime (ibid:5).

The availability of cell phones has changed the way people act and interact. Cell phone coverage in some countries now reaches far into the rural areas where previously there had been no landlines. Being able to communicate regardless of location allows individuals to remain in contact regardless of the distance. In South Africa, for example, there is a large movement of people from the rural areas to the urban spaces. Cell phones have allowed families to stay connected as well as provided economic benefits. Economist Jeremy Sachs argues the mobile phone phenomenon to be “the single most transformative technology for development” (Etzo, 2010: 3). While he is referring to the economic realm, the idea of mobile technology for development is also being applied to the social sector in the form of ICT4D.

#### *2.2.2.1 Cell Phones for Social Good*

Mobile technology is also being used to support social good. In Nigeria, mobile technology has been used for “political applications as a means to improve transparency and accountability” (ibid: 6). During the 2007 national elections, volunteers stayed close to the polls and sent in their observations to a central database. The information they provided was then used by international

organisations such as the European Union to monitor the potentially volatile situation (Etzo, 2010).

To address the issue of counterfeited medication being sold in Ghana, a mobile start up called mPedigree has a service which allows people to check whether a pharmaceutical is counterfeit. The user sends a code displayed on the pharmaceutical to the service and the service almost immediately sends a reply in the form of an SMS confirming whether the medication is legitimate. This allows users to have confidence in their medication and suppress the worry that it might be an imitation (Etzo, 2010: 5).

These programmes which utilise mobile technology to address health issues are becoming increasingly popular and adding to the growing field of mHealth.

### ***2.2.3 Cell Phone Based Programmes and mHealth***

Mahmud (2010: 138) argues that the number of cell phone users and cell phone signal coverage has made “[cellular] communication platforms an opportunistic solution” to complex social issues such as the HIV/AIDS pandemic. Because the cell phone is an already popular ICT device, cell phone technology is therefore a strong starting point for development projects. The Joint United Nations Programme on HIV/AIDS [UNAIDS] as well as the World Health Organization has recognised the importance of the cellular platform and now include wireless communication strategies in their strategic plans (Lester et al, 2010). In recent years the number of ICT4D projects looking to utilise the cellular phenomenon has grown at a dramatic rate. In particular, ICT4D programmes are being directed at South Africa’s startling health issues including the treatment and prevention of the HIV/AIDS pandemic and tuberculosis.

While the term “e-health” is used to describe health initiatives which employ electronic methods such as computer technology, the internet, cell phones, etc, the term “mHealth” describes those initiatives which specifically utilise mobile or cellular technology. The definition includes various functions of cell phones such as SMS, multimedia messaging service [MMS], and in some cases mobile internet (Michael et al, 2010). mHealth initiatives are popular for addressing the HIV/AIDS pandemic because of their ability to transmit and receive information no matter how remote the location. “Mobile coverage in the developing world is rapidly increasing. Its reach is greater than any other technology or health-related infrastructure. By 2012 an estimated 50% of those living in remote areas will have mobile phones” (Leach-Lemens, 2009: 2). This is extremely important for organisations attempting to reach a large number of people in the most efficient manner (ibid: 2). Not only does mobile technology allow for a greater reach, but certain characteristics of the technology appropriately address issues unique to HIV and AIDS.

#### *2.2.3.1 The mHealth Response to Stigma associated with HIV/AIDS*

Stigma is an undeniable part of the HIV crisis in South Africa (Kalichman, et al 2003; Skinner & Mfecane 2004; Bogart, 2011). According to a national survey, “26% of respondents would not be willing to share a meal with a person living with AIDS, 18% were unwilling to sleep in the same room with someone with AIDS, and 6% would not talk to a person they knew to have AIDS” (Kalichman, et al, 2003: 442). This mentality towards the disease makes HIV disclosure, or even showing an interest in related information, an intimidating experience. The option to remain as anonymous as possible yet still have access to information is paramount and mHealth is able to provide just that. The idea of being anonymous is important for those who would like information regarding stigmatised diseases without having to reveal their interest to other people. A recent study (Kalichman et al, 2003) reported that the level of stigma associated with HIV/AIDS testing in the townships surrounding Cape Town is especially high. Of the 488 participants, only 44% indicated that they had undergone some form of Voluntary Counselling and Testing (VCT). Of

the 53% that indicated that they had not gone for testing, many reported having conditions such as Sexually Transmitted Infections (STIs) and genital ulcers which makes people more susceptible to the virus and would place them at high risk for being HIV positive. Researchers also found that most of the participants were aware of the severity and their own susceptibility to the disease. This led to the conclusion that a significant factor as to why individuals did not seek VCT was not an unawareness of HIV/AIDS but rather the fear of being stigmatised (ibid).

#### *2.2.3.2 The mHealth Response to HIV/AIDS Testing and Medication*

For final confirmation of an individual's HIV status, that individual must be tested at least twice. The 'window period' of possible error is approximately three months; many people, however, do not go back for a second test. Mobile phones provide a direct link to the individual and can be used to remind people to go back for a second test. Another component of HIV/AIDS that is crucial yet often neglected is the adherence to medication. The medical regime needed to fight HIV consists of several different drugs, the combination of which is referred to as Antiretroviral Therapy or ART. In order for an individual to avoid developing a resistance to ART, they must follow the regime carefully. Failure to do so results in the current ART becoming ineffective and therefore places that individual in need of a new ART combination. Because of the limited number of ART routines available, the consequence of drug resistance can be fatal (Dybul, Fauci, Bartlett, Kaplan, Pau, 2002). Results of a study done in Kenya (Lester et al, 2010) show that HIV positive patients that received SMS reminders to adhere to their ART regimen were more likely to have virus levels suppressed to a point below detection. In the United States, "mobile health technology interventions are gaining a clear evidence base for management and prevention of a broad range of disorders" (Lester et al, 2010: 1843).

### *2.2.3.3 mHealth Studies in South Africa*

A study done at a health clinic in Gugulethu, South Africa (Donald et al 2007) showed that cellular communication had a positive impact on the communication between HIV counsellors themselves and between the counsellors and patients. The counsellors reported positive feelings towards the ease they now had in reaching their patients. The counsellors also felt confident that the ART reminders received by their patients helped in maintaining their patients' adherence rates.

Crankshaw et al (2010) also examined the effect of cell phone technology being used to promote the ART adherence of patients from a hospital in the KwaZulu-Natal province. The authors did not simply test whether ART adherence was positively or negatively affected; they also tested for basic patterns within cell phone use. Their research brings up some interesting questions regarding how the participants used their cell phones in general. Firstly, the authors report that 28% of their respondents said that they shared their cell phone with one or more persons. Of this 28%, the portion of females that shared phones was significantly higher than that of males. 25% of the respondents reported that they believed someone else had read their SMSs without their permission at some point (ibid: 731). If cell phones are to be used to address stigmatised issues such as HIV, cell phone privacy and ownership may be a major stumbling block in reaching the most vulnerable populations.

Parker, Wills, and Wills' (2010) research found that their cell phone technology based counselling programme benefited the recovery of ex drug addicts and ex gang members living in the Cape Flats outside of Cape Town. These programme users became more open and willing to receive help and advice in their recovery; a result that the researchers attributed to the anonymity that the technology affords to users. The positive results encourage further research into the connection between South African community and human development and cellular technology.

The results provide hope that the same success can be found when ICTs are applied to other social challenges. Cumulatively, these studies provide a solid starting point for understanding the potential impact of cell phones on the treatment and prevention of HIV/AIDS.

#### *2.2.3.4 Critique of mHealth Studies*

Although mHealth has seen success, even in its early stages, there is one glaring criticism seen consistently within the field. Many mHealth programmes, initiatives, and interventions have not used behaviour or health theories to inform the methods employed for achieving their overall goals (Leon & Schneider, 2012; Machael et al, 2010). From a policy white paper on the barriers and gaps of mHealth in low and middle income countries:

The field of mHealth has yet to embrace behaviour theory to underpin its projects. We know that mHealth ‘works,’ in the sense that data can be successfully collected, but only understanding the behavioural and psychological processes that underlie the health behaviour change aspects of a programme will we have a complete grasp of the system (Machael et al, 2010: 29).

mHealth as a concept is still in its infancy, but is growing rapidly in order to keep up with the mobile phone revolution in Africa. According to Etzo (2010: 3), “the mobile phone industry’s failure to predict the spectacular growth of the [mobile phone] market in Africa was also echoed by shortcomings in the research community, and the reluctance of some of the NGOs to adopt this new technology.” He argues that it is actually the speed with which mobile phones became popular in Africa that accounts for the lack of theoretically grounded programmes.

In 2003, Vodafone published a paper on the impact of mobile phones in Africa in which the literature reviewed revealed “little systematic evidence” about the possible influence mHealth

programmes could have which was due to the lack of theoretical underpinning (ibid). This has proved to be a major downfall in mHealth so far. In order to address this oversight, I have used a health behaviour theory in my action research. In the following section, I will review the importance of theoretical grounding as well as unpack the theoretical model used in the SMS based programme which I subsequently aided in creating and also evaluating.

### **2.3 Theoretical Grounding**

*Theory is “an abstract, symbolic representation of what is conceived to be reality – a set of abstract statements designed to ‘fit’ some portion of the real world.”*

*(Zimbardo et al, 1977: 53)*

Previous mHealth studies have been effective in highlighting the growing field of mHealth and substantiating the work with data collection (Parker et al, 2010; Crankshaw, 2010; Donald, 2007). However, a major gap in mHealth at the moment is the lack of behaviour theory underpinning the studies.

Theories are crucial in that they aid in finding patterns in the way life manifests itself, allowing researchers to make reasonable predictions about how the world works. Originally in Western thought, theory and practice were seen as two different entities; however, 20th century philosophers attempted to reconcile the differences. Philosopher John Dewey described empirical investigation, otherwise known as research, as the middle ground between theory and action (Glanz et al, 2008: 24). Glanz argues that, especially in health education and behaviour, Dewey’s methods should be employed. Furthermore, “the best theory is informed by practice; the best practice should be grounded in theory” (24). Brewer and Rimer (2008: 150) highlight that theory provides a link between the findings of various studies. Theories with well identified constructs

allow researchers to easily facilitate the comparison of different studies and who, in turn, can hopefully add to the knowledge base.

In regard to planning programmes, theories assist in guiding the search of why, what and how. These questions are especially important when applied to public health. However, in health behaviour, the influential guiding concepts can be too complex for a single unified theory. Models, which combine concepts from a number of theories to help understand a particular problem, are therefore often employed (Glanz, 2008: 29). In order to understand how participation in a mHealth programme affects the user's health behaviour, I have chosen to continue in the vein of Dewey and more recently Glanz, Brewer and Rimer and utilise the Health Belief Model to guide my research as well as inform my decisions during the creation of the programme content (Brewer & Rimer, 2008).

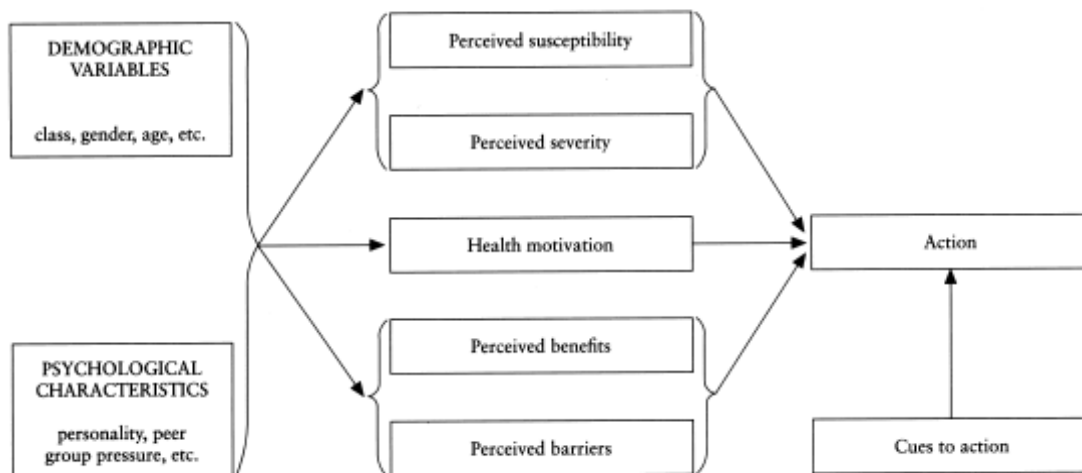
### ***2.3.1 The Health Belief Model***

The Health Belief Model [HBM] has been consistently used within health behaviour research since the model's creation in the 1950s (Champion & Skinner, 2008: 45). It began as a way to explain the persistent failure of the American public to participate in programmes to prevent and detect disease and later was also used to assess people's behaviours in response to various diagnosed illnesses with a particular focus on medical regimens (ibid: 46). The model has several basic concepts that predict "why people will take action to prevent, to be tested for, or to control illnesses conditions; these include susceptibility, seriousness, benefits and barriers to action...and most recently, self efficacy" (ibid: 46-47). It is especially useful in that it is open to interpretation and slight adjustment. For example, Abraham and Sheeran (2005: 30) have expanded the concepts to include health motivation.

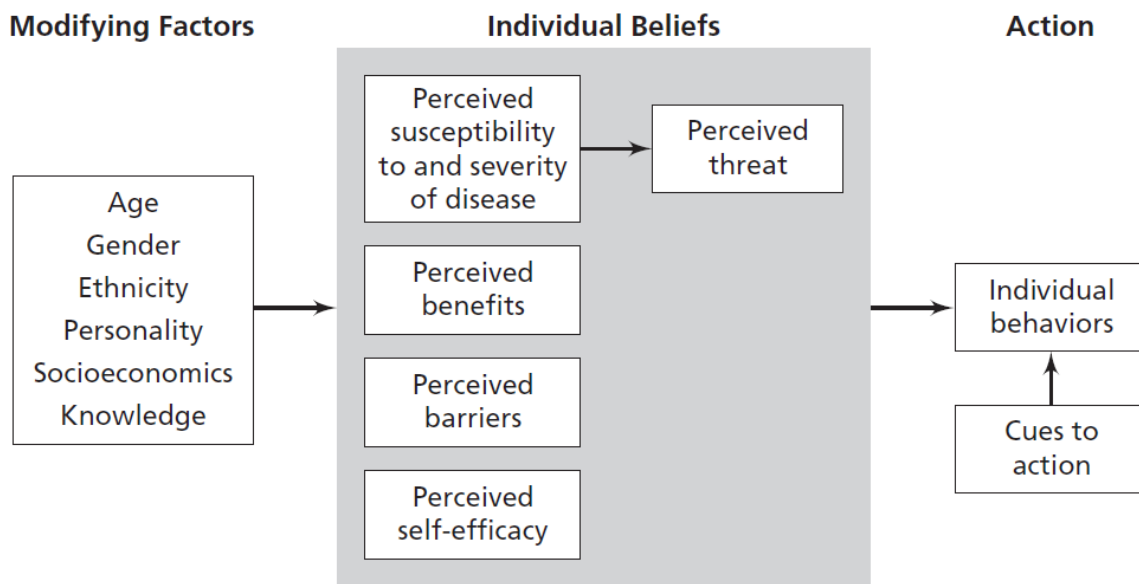
With the exception of the inclusion of self efficacy in the version by Champion and Skinner (2008) and that of health motivation in the version by Abraham and Sheeran (2005), the constructs within these two variations of the HBM are essentially the same. Both models acknowledge that basic demographic variables such as age, gender, personality, socioeconomic status and knowledge play into one's thoughts and attitudes. However, because demographic variables, unlike the other 'individual beliefs,' cannot be modified, the HBM is valuable for programmes which hope to influence the behaviour of people from varied demographic backgrounds (Abraham & Sheeran, 2005: 28).

The following are two different variations of the HBM.

Figure 2. Health Belief Model reproduced from Abraham and Sheeran (2005)



**Figure 3. Health Belief Model reproduced from Champion and Skinner (2008)**



Perceived susceptibility refers to whether an individual believes that a certain illness or disease has the potential to affect them and how great the threat actually is. Perceived severity is the level of seriousness an individual places on the contraction of disease or illness in terms of medical consequences such as disability or death and also in terms of social consequences such as social relations or the ability to work. Perceived benefits refer to the benefits the individual will accrue if the individual successfully avoids, tests for, or undergoes action to control the disease or illness. Perceived barriers refer to the potential negative aspects that may act as deterrents in undertaking the recommended behaviours. This individual could, for instance, believe that the recommended behaviours are too expensive, unpleasant, or lengthy for their liking (Champion and Skinner, 2008: 47-49).

Self efficacy, found in Champion and Skinner’s (2008) model, is defined by Bandura (1997) as “the conviction that one can successfully execute the behaviour required to produce the outcomes” (Champion and Skinner, 2008: 49). Because the HBM was initially used to test people’s resistance to undergoing various immunisations, the model did not have to address complex feelings such as efficacy. However, as the model was expanded to include medical

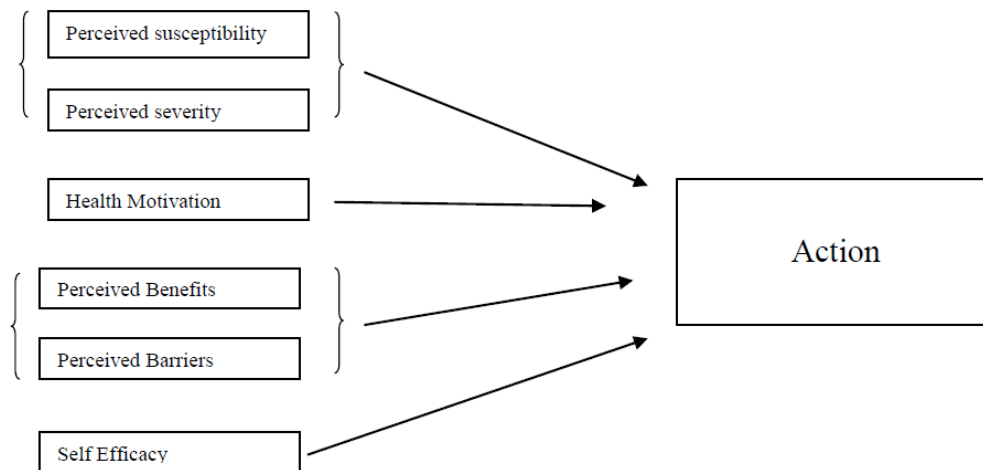
adherence and prevention of diseases that do not have immunisations, it was necessary to include self efficacy to capture this important emotional construct which accompanies behavioural change (Champion and Skinner, 2008: 49; Rosenstock et al, 1988:179 ). Rosenstock et al (1988) proposed that self efficacy be added to the HBM because of its importance; ensuing studies that tested the predictive power of the HBM including self efficacy confirmed that it is a useful predictor (Abrahams & Sheeran, 2005: 41).

Finally, Abrahams and Sheeran, define health motivation as “an individual’s readiness to be concerned about health matters” (2005: 30). The constructs of the HBM hope to predict the action an individual will take in regard to a certain disease or illness. However, Abrahams and Sheeran (2005) assert that the series of cognitive antecedents which act as the constructs of the HBM are actually predictors of intention rather than behaviour. They argue that behaviour is influenced by far more complex components than the cognitive antecedents used in the HBM. Therefore, “it may be prudent to regard HBM-specified beliefs as antecedents of intention rather than predictors of behaviour” (2005:43). Such a stance may account for situations in which the HBM is unable to accurately predict behavioural choices.

Cues to action is a construct that was included in early HBM interpretations. It is meant to include the various events that may inspire an individual to take action. Such events could be bodily, like unwanted symptoms becoming visible, or they might be environmental, such as a focused campaign to be tested for HIV. Because of the ambiguity, this particular concept has actually never been empirically studied. It’s been argued that literally anything can cue an individual to action and therefore that cue may be subconscious or too small to be noticed by the individual which in turn, makes the concept very difficult to examine with an explanatory survey (Champion & Skinner, 2008: 49). Not only is it difficult to measure but it is also difficult to address in an intervention that utilises the HBM. Therefore, for my purposes, cues to action will

be left out of the model that drives the “Just Tested for HIV” Programme. However, the fact that it cannot easily be measured or altered does not mean that the cues to action component is not an important factor in understanding an individual’s reception to HIV interventions. Within the construction of the programme for this research, there is no way to address cues to action in a sufficient manner. In order to best serve the scope of my research, I used an adjusted form of the Health Belief Model.

**Figure 4. The Health Belief Model I am applying:**



Although the HBM has been used over the decades to predict health behaviours, it is not without fault. There are some weaknesses to the model which I will now discuss. I have taken the weaknesses into account and will acknowledge these in my methodology.

## ***2.3.2 Analysis of the Theoretical Model***

### *2.3.2.1 Background*

As previously mentioned, the HBM was created in the middle of the twentieth century by social psychologists from the United States Public Health Service with the aim to understand why large portions of the public refused to participate in tuberculosis screening programmes (Champion & Skinner, 2008; Abraham & Sheeran, 2005). These social psychologists developed the model out of two different learning theories: Watson's Stimulus Response Theory (1925) and Tolman's Cognitive Theory (1932) which was later adapted by Lewin in 1951. Stimulus Response Theory postulates that an individual's behaviour is dictated by various rewards one receives upon completing certain behaviour as well as the temporal relationship between the action and the reward. If the particular behaviour is rewarded and done so within a short period of time, then Stimulus Response theorists believe that the desired behaviour can be expected from the individual.

Cognitive theorists, on the other hand, believe that behaviour is not dictated by the actual reward associated with the behaviour but rather with the various expectancies associated with the behaviour. Key factors in cognitive theories include reasoning, thinking, and expecting. Therefore cognitive theories postulate that rewards affect expectancies rather than directly effecting behaviours (Champion & Skinner, 2008). The cognitive theories that eventually specialised in health related behaviours and later came to influence the HBM were based upon two general assumptions. One, that individuals "value avoiding getting illnesses/ getting well and (2) expect that a specific health action may prevent (or ameliorate) illness" (ibid: 46).

The constructs of the HBM (perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self efficacy) are all very closely tied to the thinking and expecting factors that are so critical to cognitive theories. The HBM has stayed grounded in its

original form but has seen various modifications. The most recent adjustment, Bandura's concept of self efficacy (1997), gave the HBM further validity with more complex health behaviour. Although the model allows for alterations to better fit specific situations, it is not without flaw. Other models which I considered and the reason for selecting the HBM will be reviewed in the following section.

### *2.3.2.2 Alternatives to the Health Belief Model*

The HBM is categorised as Social Cognitive Theory [SCT] which is named as such due to its prediction of social behaviours. While the HBM was created specifically to address a health issue, other SCTs also possess beneficial predictive power.

The Theory of Planned Behaviour [TPB] assumes that behavioural intention is the best predictor of behaviour (Montano & Kasprzyk, 2008). The TPB is beneficial in that it recognises intention as the basis of behaviour. It has been suggested that the HBM should rather be viewed as a model predicting intention as opposed to actual behaviour. However, the model that accompanies the TPB (ibid) is not specifically geared towards health behaviour and as such has less specific (therefore more easily misguided) constructs.

The Social Cognitive Theory (Bandura 1982) is widely used in predicting health behaviour. The HBM has been greatly influenced by this key psychological theory; namely in the use of self efficacy as a construct. Self efficacy was believed by prominent social cognitive theorists (Rosenstock, Stretcher, and Becker, 1988 – in HB and HE) to be the missing piece to the HBM and was officially suggested as a permanent construct in 1988. The HBM and the SCT also share outcome expectancy as a construct. They are indeed closely related. However, again I have chosen the HBM as my model because its intended purpose was to predict health behaviour and, because of that, contains health specific constructs.

### *2.3.2.3 Critique of the Health Belief Model*

While the use of the HBM is flexible and can be interpreted to fit a range of situations, it is difficult to anticipate whether the model is appropriate to use even if it has been utilised by similar studies in the past. For the HBM to be successful, the constructs must be made relevant to the context and culture of the case. Cultures and contexts are full of nuance which inevitably makes them incomparable to others. However, many of today's most pressing health issues transcend culturally demarcated borders. In terms of HIV/AIDS related behaviour, research has shown that different groups of people have different psychological triggers, beliefs, and expectations about the disease. For example teenage men differ from women, different age groups of people often have differing beliefs, and North American individuals have different motivators as compared to African individuals (Aspinwall et al. 1991; Richard and Van der Pligt 1991; Abraham et al. 1994; Schaalma et al. 1993). Within a group of HIV positive, American gay men, it was found that believing one's self to have a high level of susceptibility did not actually lead to behavioural change (in this case, condom use). It was hypothesised that perhaps increased susceptibility within certain groups lead to individuals caring less about behaviour modification. For example, if a man believes that his susceptibility is so high that he is very likely contract HIV, he may not care about avoiding the disease (Abraham & Sheeran, 2005: 51).

Another weakness within the HBM is that self efficacy is the only mentioned psychological barrier to behaviour change. Especially in the case of diseases with complex social consequences such as HIV/AIDS, individuals may face psychological issues other than self efficacy. For example, the HBM does not account for poor understanding of complex recommendations (Abraham & Sheeran, 2005: 49) or social pressures that are not covered under self efficacy.

## **2.4 Summary**

Although the HBM is not without flaw, “many research studies have identified relationships of HBM constructs with safe sex behaviours” (Champion and Skinner, 59). The HBM was created to specifically address health behaviour issues and as a widely recognised model, it was applied to the mHealth landscape for this study. My intention with this chapter was to situate to my research question into a historical context and existing research. In acknowledging its place within the history of development, I hope to provide a more thorough appreciation of mHealth and its importance. In the following chapter, I will outline my methodological processes including the way in which the HBM influenced the creation of the programme used for this research as well as my data collection and approach to analysis.

University of Cape Town

# Chapter 3. Case Study

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In the following chapter I will highlight the study design, the organisations that created and contributed towards the “Just Tested for HIV” programme. I will situate their importance within my action research, and explain the creation process behind “Just Tested for HIV.”

## 3.1 Case Study Design

This research is a single case study design and is explanatory as well as descriptive. Because I, as the researcher, was involved in the creation of the programme that acts as my case study, the research qualifies as action research.

Through this dissertation I attempt to answer three primary research questions:

1. How is mHealth being used to address HIV/AIDS in South Africa?
2. Can mHealth programmes be successful in supporting the treatment and prevention of HIV/AIDS?
3. How was the “Just Tested for HIV” programme received by the participants?

I undertook this endeavour to expand the mHealth knowledge base in South Africa as it is a growing field with massive potential to change the landscape of public health oriented development. I worked in conjunction with Cell Life, the principal creators of the “Just Tested for HIV” programme, for nine months (December 2011 – September 2012) during which time I collaborated with Dr. Victoria Nembaware, the mHealth projects coordinator, in conceptualising, creating, and piloting the “Just Tested for HIV” programme. After piloting the project, I interviewed a group of programme users at the midway point of their participation to understand their experience with the programme. The research hopes to describe the participants’ attitudes and ideas about their cell phones, any changes in behaviour that were self reported after

participating in the programme, and the way in which they use their cell phones, all as it relates to their HIV status and their participation in the “Just Tested for HIV” programme.

## **3.2 Organisation Background**

In order to engage in action research, for my data collection, I worked very closely with an organisation called Cell Life to create and then assess one of their programmes. Cell Life designs mobile technology programmes yet it does not have direct access to people for whom these programmes are intended. To address this issue, they partner with other organisations in order to reach the public. For the “Just Tested for HIV” programme, Cell Life partnered with an organisation called Right to Care to pilot this intervention. I will now give brief backgrounds to both Cell Life and Right to Care.

### **3.2.1 Cell Life**

Cell Life is an organisation that specialises in mobile health technology. According to their website<sup>3</sup>, they are an:

“organisation that provides technology-based solutions for the management of HIV and AIDS and other infectious diseases such as TB. Cell-Life's primary function is to address health-related logistical challenges in developing countries, such as the provision and distribution of anti-retroviral treatments, continuous patient monitoring and evaluation, and collection and communication of relevant data. This is achieved through the use and development of innovative software supported by existing technologies such as mobile phones and the Internet, in a manner that is appropriate for a developing-country context.”

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<sup>3</sup> [www.cell-life.org](http://www.cell-life.org)

I proposed to Cell Life that I undertake a study of one of their programmes for this dissertation. They then suggested that we work together in creating the “Just Tested for HIV” programme and that I use this programme as a means to conduct my research. The way in which outcome of this agreement is described later in the chapter.

### ***3.2.2 Right to Care***

Right to Care is a nationwide organisation which “builds public- and private-sector capacity for the clinical [sic] care and treatment of individuals living with HIV and associated diseases”<sup>4</sup>. Right to Care has many functions, one of them being the provision of mobile clinics that test people for HIV/AIDS. The Right to Care branch in Hermanus, Western Cape focuses primarily on that. Cell Life and I approached Right to Care Hermanus (from here referred to as Right to Care) to assist in piloting the “Just Tested for HIV” programme.

### **3.3 Action Research**

Action research “involves practitioners in the research process from the initial design of the project through the data gathering and analysis to the final conclusion and actions arising out of the research” (Whyte, 1991: 7). Although I did not initially intend to use action research methods, my work took this form after Cell Life approached me to assist them in the creation of the “Just Tested for HIV” project. Many definitions for action research are available, however one that is quite applicable is as follows:

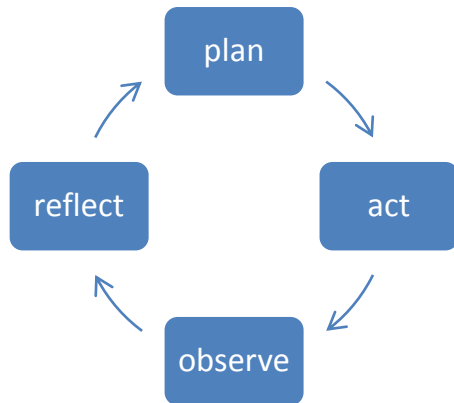
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<sup>4</sup> <http://www.facebook.com/rctsa/info>

“Action Research is a flexible, spiral process which allows action (change, improvement) and research (understanding, knowledge) to be achieved at the same time” (Costello, 2003:3).

The following model describes the general action research process;

**Figure 5. Action research model (Costello, 2003:13.)**



My research closely followed the circular direction of the general action research model. I *planned*, alongside Dr. Nembaware, how to best create the content for the SMSs that would be sent out in the “Just Tested for HIV” programme. We used the Health Belief Model to guide our strategy. I *acted* with Dr. Nembaware in recruiting a partner organisation who could pilot the “Just Tested for HIV” programme and by contributing towards the testing of the programme’s technological functions. I *observed* user participation by way of in depth, qualitative interviews. Finally, I *reflected* by analysing the data that I collected from the research. This reflection then went into a report for Cell Life in order for it to make the programme more effective.

Contributing towards a more highly functioning programme while at the same time conducting research for my own purposes, as well as the advancement of Cell Life, was a rewarding experience. To a certain extent, the active involvement that comes from action research manages to address various ethical issues that accompany humanities based studies. Far too often students

will use disadvantaged populations for their own academic advancement meanwhile leaving these communities to carry on as they were. Through action research, however, strategies can be devised in which research and action are closely linked (Whyte, 1999). Action research is thus able to tackle the issue by allowing the researcher or student to make a contribution to academic knowledge as well as aid in the improvement of human welfare (Babbie & Mouton, 2001).

Being a part of the creation for the “Just Tested for HIV” programme, allowed me to facilitate in the design of what would become my case study. In the next section, I outline the processes of the construction of “Just Tested for HIV.”

### **3.4 Creation of the “Just Tested for HIV” programme**

#### ***3.4.1 “Just Tested for HIV”***

The “Just Tested for HIV” programme was conceptualised as an SMS based programme that would be offered at various HIV testing centres to individuals after they had undergone an HIV test. The service would be provided to all individuals who tested, regardless of their HIV status. The content of the SMSs, although differing depending on the individual’s status, was meant to be informative, encouraging, supportive, and helpful in assisting people with managing their health. Upon review of Dr. Nembaware’s plans, I found there to be no theoretical basis to the content being distributed through the SMSs. As per my suggestion to consider the Health Belief Model (Champion & Skinner, 2008; Abraham & Sheeran, 2005), Dr. Nembaware decided that we should collaborate to use the model to create the content for this intervention.

Cell Life had created a similar programme in the past which also provided HIV/AIDS information and support through SMSs. We used that content as a baseline in creating the SMSs for the new “Just Tested for HIV” programme. Many of the original SMSs supported the HBM

and therefore were useful. However, we made many alterations and additions so that all constructs of the HBM were covered. Before piloting, a needs assessment was conducted in order to verify that we would be suiting the needs of the community at hand. To do so, Dr. Nembaware and I accompanied one of the Right to Care mobile clinics to one of their regular locations. We spoke to people while they were waiting in the queue for the Right to Care services. The assessment covered topics such as cell phone ownership, openness to SMSs, and preference in content. A copy of the needs assessment can be found in the appendix section. The information collected was also used to inform the SMSs as well as the programme structure.

### ***3.4.2 The Health Belief Model and SMS Content***

As indicated in the Literature Review, the HBM (Champion & Skinner, 2008; Abraham & Sheeran, 2005) consists of various constructs that in turn predict an individual's health behaviour.

*See figure 4.*

Following this model, I hypothesise that if the SMS content was driven by the six constructs of the Health Belief Model then the "Just Tested for HIV" intervention would be more likely to influence its participants' health behaviour. The model indicates that in order for individuals to make changes in their health behaviour they must:

Perceive themselves to be susceptible to the health threat. Although HIV/AIDS is rampant in South Africa, humans possess certain psychological self preservation tactics that allow us to feel that we are not at risk to threats that surround us (De Lannoy, 2008). Although this tactic has its purposes, it can be detrimental to people living in areas with high HIV rates. Therefore, in the SMSs sent to HIV negative participants, some content focused on susceptibility to HIV. For example:

*Hello again. Being HIV negative does not mean you cannot get infected! Practice safe sex. Stick to one partner and always use a condom.*

For HIV positive participants, susceptibility content focused more on the susceptibility of contracting AIDS and other health complications:

*Many people living with HIV wait for too long before going to the clinic to start ARVs.*

*Don't wait until you are sick; get your CD4 cell count checked as soon as possible!*

Perceive the threat to be severe. If an individual believes that contracting HIV is “not so bad” then they will be less likely to behave in ways that help prevent contraction. However, Dr. Nembaware and I were conscious not to construct content that would potentially increase the stigmatisation of HIV when intending to speak about severity. Therefore, for HIV negative individuals, severity content attempted to address the gravity of contracting HIV in a way that did not resemble “scare tactics”:

*1/3 of HIV+ people in South Africa are between 15 and 25. Talk to your teens about staying safe. The national AIDS helpline has more info: 0800 012 322*

The same consideration of stigma was given to the content for HIV positive participants while constructing messages that addressed the severity of not managing the disease well:

*Hi. HIV weakens the immune system, meaning 'opportunistic infections' can attack more easily eg TB, pneumonia, and diarrhea. More tomorrow.*

Have an adequate level of what Abraham and Sheeran (2005: 30) call “health motivation.” Their model (Abraham and Sheeran, 2005) suggests that to make positive health choices, individuals must have a strong inclination to do so. For HIV negative

individuals health motivation included commending any positive steps they had already taken and encouraging them to continue in this vein:

*Hi there! When you meet someone new... before you get too involved in the relationship, get tested together. You're responsible for your health, and each other!*

For HIV positive individuals, health motivation, in terms of the HBM, meant to act as an inspiration for changing their lives for the better. For example:

*In order for you to live with HIV successfully, you've to say "You know what? This is my body, this is my life. I'm not going to stop living."*

Perceive that they will be benefitted by their actions. Individuals must believe that taking positive behaviour steps in terms of HIV will lead to benefits that outweigh any costs in regard to time, effort, etc of the action. HIV positive individuals were reminded of the benefits of maintaining a healthy, safe lifestyle regardless of HIV status:

*HIV doesn't mean no sex! ALWAYS use a condom so you don't pass it on. Even if your partner is also HIV+, cause you can give each other different kinds of HIV.*

For HIV positive individuals, the 'perceived benefit' SMSs served to remind the participants about the positive outcomes they could expect if they make positive behaviour choices in relation to their HIV:

*It IS possible for a couple to have an HIV-negative baby together, even if one of the parents is HIV-positive. For more info, ask at the clinic.*

Perceive that the barriers to undergoing positive health behaviour are not too great that they cannot be overcome. For HIV negative individuals, this meant addressing any fears or concerns they may have about taking steps to remain negative. The following SMS

offers the participant some advice on how to get tested without having to visit an HIV specific clinic:

*Donating blood is a good thing to do both for those who might need the blood & for yourself. Each time you donate blood, your blood gets tested for HIV.*

For participants who are HIV negative, the content addressed barriers one might face in regard to taking steps to staying negative such as not knowing anyone to speak to or not having any place to ask questions:

*Hi. If you have questions or need support about HIV & AIDS, please call the AIDS Helpline 0800 012 322, free from a landline. Call any time of day or night.*

Have the self efficacy, or ability, to undergo the necessary actions. For HIV positive participants, the content was focused on the ability to live a long, healthy life:

*You have the power to take charge of your health and your life. Stay informed by visiting your clinic or watching programmes like Beat it/ Siyayinqoba on SABC 1*

HIV negative individuals received similar messages:

*Staying HIV negative isn't difficult but it takes responsibility. Always use a condom and get tested regularly. A programme like "Beat It" on SABC 1 has more*

The constructs of the HBM can be fairly ambiguous. For example, information that may encourage an individual's readiness to make healthy decisions (health motivation) may also fall into the category of self efficacy. It was made sure that the different constructs were covered evenly throughout the forty final SMSs. However, to deal with the ambiguity, some SMSs were categorised as two different constructs (e.g. self efficacy and health motivation).

### 3.4.3 Communicate System

After writing the SMSs, they were loaded onto Cell Life’s Communicate computer programme. Communicate is responsible for most of the technical functions of the “Just Tested for HIV” programme. Among other functions, it records the phone numbers which sign up for the intervention, automatically sends those phone numbers the appropriate SMS each day, and it tracks the phone numbers which opt out of the programme prior to its conclusion. In order for the SMSs to be sent out, they must first be ‘loaded’ onto Communicate. Below (figures 6, 7, and 8) are a few screenshots of the communicate interface throughout the loading process.

Figure 6. Communicate login screen:

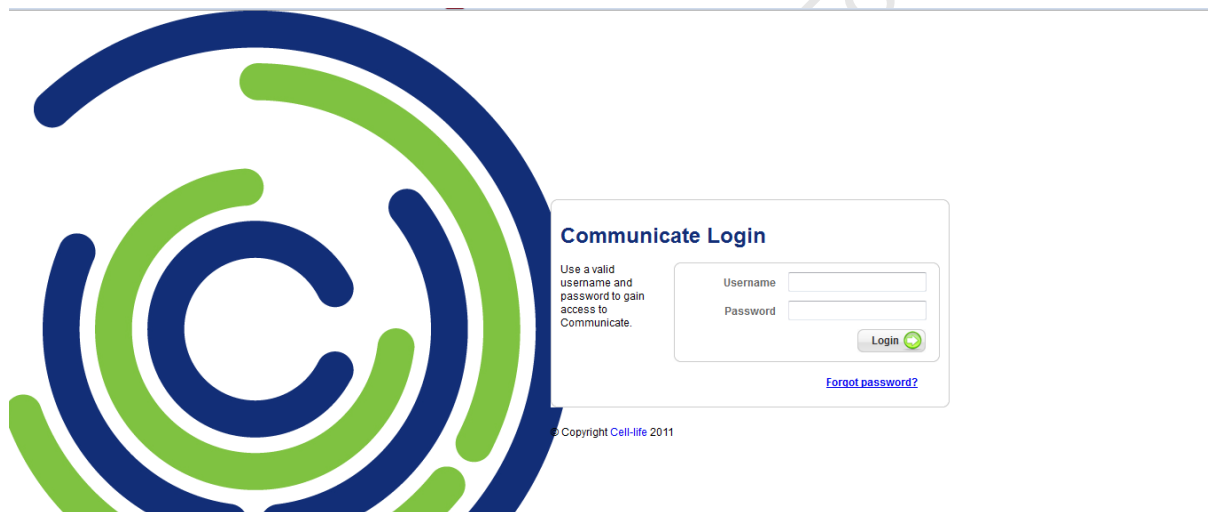
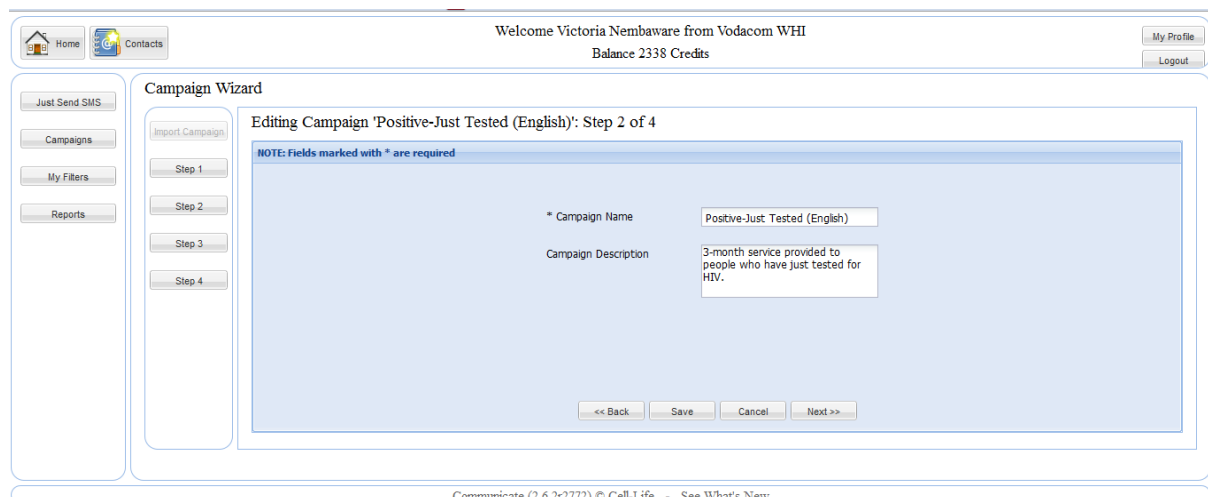
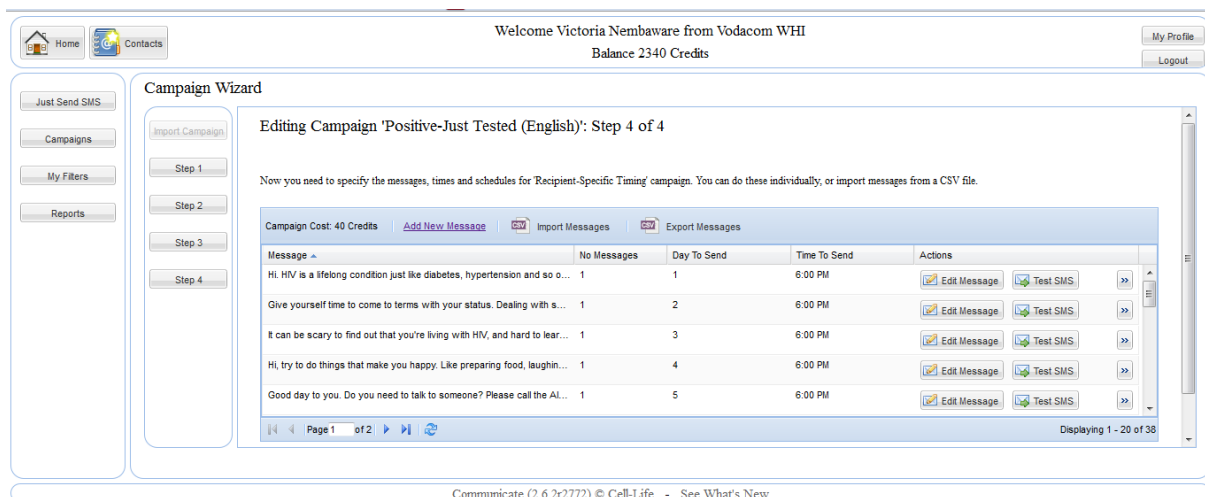


Figure 7. Screen shot of the English SMSs for HIV positive programme users:



**Figure 8. The Communicate interface including successfully loaded SMSs:**



### 3.4.4 The Users' Experience with "Just Tested for HIV"

To sign up for the "Just Tested for HIV" programme, individuals are directed to send a "Please Call Me" [PCM] SMS to a particular phone number. There are six phone numbers provided: there are separate lines for HIV negative and positive individuals in English, Afrikaans, or isiXhosa. These phone numbers are managed by the Communicate programme. After sending this PCM, the individual receives an SMS welcoming her/him to the programme and reminding her/him how to unsubscribe if they wish to do so. For the following 30 days, the individual receives a daily SMS at approximately 18:00. For the remaining 60 days of the programme, the individual receives one SMS per week. The reasoning behind the three month time frame is so that participants, especially those that tested negative for HIV, are reminded to test for HIV at the conclusion of the window period. HIV tests look for antibodies caused by the virus in a person's bloodstream. However, these antibodies may not be visible until up to three months after the virus has been contracted, hence the three month window period. Therefore, participants in the programme are encouraged to follow up on their HIV test to ensure an accurate diagnosis.

### **3.5 Summary**

After contacting Cell Life, it was decided that I would collaborate with the organisation in creating the “Just Tested for HIV” programme. The content that the programme provides its users was driven by the ideas put forth by the Health Belief Model. To access individuals, Right to Care was approached to assist in piloting this programme.

As a researcher, I found it valuable to have been able to take part in action research and have a hand in the creation of the programme which became the basis of my case study. In the following chapter, I will outline case study methods, the research methods, and the methods of analysis that I employed.

University of Cape Town

# Chapter 4. Methodology

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The primary goal of this dissertation is to assess the way in which a focused group of individuals participating in Cell Life's "Just Tested for HIV" programme view and engage with health related messages received via cell phone SMS through action research in a case study design. This chapter describe the methods I have employed in order to achieve this. The chapter will provide a background of the organisations with which I collaborated, the research design, the creation of the "Just tested for HIV" programme, my case study framework, the research methods, the method of analysis, and finally the research considerations. Due to the nature and involvement in my research, I have chosen to use separate theoretical bases for the research and the analysis. The chapter will discuss each of the theories as well as the decision to separate the two.

## 4.1 Case Study Methodology

Gerring defines a case study as an "intensive study of a single case where the purpose of that study is – at least in part – to shed light on a larger class of cases (a population)" (2006:21). I will be studying, by way of interview, researcher observation, and document analysis, the attitudes and beliefs of participants in the "Just Tested for HIV" programme. Although I am concentrating on a single programme, my hope is that my research will be applicable to the larger mHealth community within South Africa.

I have chosen the case study design in order to have the ability to produce "more detail, richness, completeness, and variance" (Flyvbjerg, 2011: 301) in my research. The majority of previous research done in the mHealth field is generally quantitative in nature. This previous research has sought to numerically identify the number of participants that experienced change in behaviour

and by what percentage (Mahmud et al, 2010; Kaplan, 2006; Lester et al, 2010; Pop-Eleches et al, 2011, etc ). I was able to find one example of a South African ICT4D project focussing on HIV/AIDS that follows a qualitative design (Donald et al, 2007). The dearth of programmes using cell phones to combat the HIV pandemic as well as my aspiration to add to the quality of research done on such programmes, led to the decision to use a single case study. The results of this study could potentially be compared to the Cell Life objectives, goals, and strategy in order to increase the program's self awareness.

Yin (2009) specifies that there are five essential components within the case study design. The design must include the study's question, its propositions, its unit of analysis, the logic linking the data to the propositions, and the criteria for interpreting the findings. My research attempts to explain how HIV/AIDS affected individuals who engage in mHealth programmes utilise their cell phones as well as how they respond to the theory-driven messaging provided by the programme. I propose that because the SMSs that the individuals receive are based in a tested theory, the participants will be more likely to engage in positive health behaviour. My "units of analysis" are the attitudes and beliefs of participants in the "Just Tested for HIV" programme as well as programme documents. I conducted in depth, semi structured interviews to gain insight as to whether the participants were engaging with the programme and assess how they view and use their cell phones. Finally, I plan to extract certain themes that are uncovered during the interviews to analyse the data collection as individual pieces and as a whole. I have adhered to this design in order to produce quality case study research.

## **4.2 Research Methodology**

### ***4.2.1 Data Collection***

The case study design allows for the research to be concentrated in a limited, controlled setting. Yin (2009) asserts that multiple sources of evidence should be used within case study research. It is for that reason that the following data collection methods were employed:

1. Participant interviews
2. Counsellor interviews
3. Researcher observation and reflection
4. Review of key documents: programme statistics including participant opt-out rates and programme refusal logs

While each aspect of data collection provided unique and important information, the most illuminating method was the semi-structured, in depth interviews. The interviews produced more information than simply the words spoken by each participant. According to Kvale (1996), research interviews are distinguished by attentiveness to the form of the question, a focus on the various modes of communication between the interviewer and the interviewee, and critical attention to the responses given. As such, knowing my own limitations, I was as observant, open, and as analytical as possible during the interactions. Yin (2009:70) explains, “‘listening’ means receiving information through multiple modalities which includes my ability to observe nonverbal cues such as body language, facial expression, and eye contact.

Interviewing as a method of data collection has been criticised by adherents of the positivist approach as being subjective and therefore unscientific. Kvale (1996) rejects this assertion and offers instead that interviews can be seen as objective in that they allow the ‘subject’ to speak freely on the matter, expressing their nature and feelings on the matter. I also look past the

positivist criticism because qualitative work gains its richness from the subjective interaction of all parties involved.

My own observations also inform the research. The ‘multiple modalities’ Yin (2009) speaks of are the basis of observation. Because the some topics covered were emotionally charged or difficult to speak about, I also sought information based on the nonverbal cues that the interviewees provided.

The review of documents is crucial to my data collection. As a researcher, I was given a unique opportunity to not only observe the effects of a programme but also be an integral player in the programme’s creation. This gives me insight into the expected outcomes of the SMSs and allows me to be more critical of the process through which they were created. This essential piece will be discussed in the Analysis Methods section.

#### ***4.2.2 Interviews***

Interviews account for the most substantial portion of my data collection in this study. Although I used an interview schedule, I let the interviews take their course and encouraged the participants to provide insight and information that I did not originally intend to collect. As compared to questionnaires or document reviews, interviews provide a multifaceted view of that which is being researched. Human interaction has the ability to provide much deeper insight than research methods that do not include face to face interaction. The majority of mHealth studies have neglected this element in their research. I hope my research contributes to the more human elements of mHealth development initiatives as the statistical side has received a large amount of the attention thus far.

#### 4.2.2.1 Selection of Participants

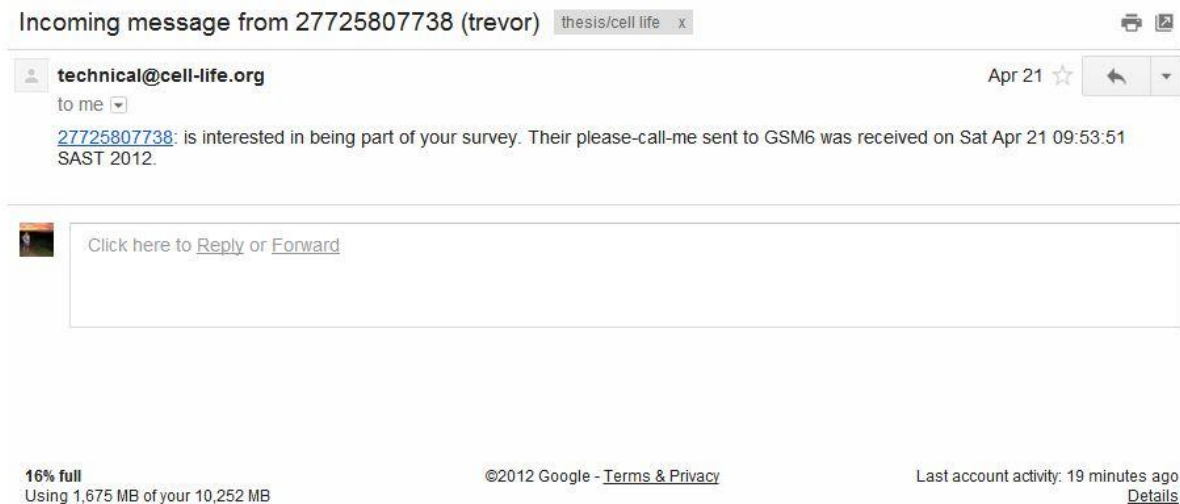
As mentioned previously, to pilot the “Just Tested for HIV” programme, Cell Life approached an organisation called Right to Care which provides mobile clinics where individuals can test for and receive information about HIV, receive a mammogram, or receive more information on male circumcision. Right to Care agreed to advertise and promote participation in the “Just Tested for HIV” programme.

After an individual tested for HIV, they were given information regarding the “Just Tested for HIV” programme (also referred to as “Just Tested”). Cell Life requested that a Right to Care nurse verbally provide information about the programme as well. The nurses kept a log of the reasons why individuals refused the service. If an individual decided to participate in the programme, they were instructed to send a “please call me” SMS to a phone number from their cell phone which, via the Communicate system, resulted in the individual automatically being enrolled in the programme. The first SMS they received welcomed them to the programme and provided instruction on how to opt out of the programme should they wish to do so at any point in time. The following day, the participant received their first informational, HIV status specific SMS. They received these SMSs once a day for one month. On the 24th day of the programme, all participants received the following SMS:

*You can be part of a survey about these SMSs! Send a please-call-me to xxx xxx xxxx by the end of tomorrow and someone will call you back with info.*

If the participants chose to send the PCM in response to this SMS, the Communicate system at Cell Life was notified. When the system was notified, it sent me an email which contained a message which looked like the following:

**Figure 9. Email from Communicate system:**



Due to complications at Cell Life and a subsequent delay in the roll out of “Just Tested”, some participants responded to the survey SMS while I was overseas. Those that did so were contacted by Dr. Nembaware who notified them that I would be in contact upon my return.

To schedule an interview, I called the participant and briefly explained my reason for calling. If the individual agreed to meet, we arranged for an appropriate time and place to do so. For some interviews, the participant required a Xhosa intrepeter. In that case, one of the Xhosa speaking Cell Life employees would assist in phoning the participant. Although, I did know the name of the participants, I will not publish the names explicitly in this thesis. Rather, I will refer to them as interviewee 1, 2, 3, etc, with the numbers referring to the order in which they were interviewed.

#### *4.2.2.2 Interview Construction*

My interview schedule was driven by a few different factors. I carried out focused interviews (Merton, Fiske, and Kendall, 1990) in which I only interviewed the participants for relatively

short, restricted periods of time. The interview schedule was used as a guide but I attempted to make the interview as open ended as possible. I considered a few issues when I created my questions. The issue of health, especially in relation to HIV/AIDS, is a sensitive topic. Although I knew that the participants are all affected by HIV/AIDS in some way, I did not want to intrude on the privacy of their health. For example, when I wished to know if the participant had learned anything new about HIV/AIDS through the “Just Tested for HIV” programme, I phrased the question indirectly (“Have you learned anything new from the SMSs?”). In this way I was able to begin with broader questions, allow the interviewee to speak about what he/she feels comfortable discussing and then ask a more specific question that was based on their previous response. After certain broad questions were asked, I employed the “probing method” (Yin, 2009; Willis, 1999) in which the answer to a broader question leads the interviewer to ask response-specific follow up questions to obtain more detail.

Kvale (1996: 133) lists various criteria for a quality interview. In these criteria he emphasises that the majority of the interview must be the interviewee speaking in order for the interviewer to obtain spontaneous, rich, specific answers from the interviewee. He also underscores the importance that the interviewer be continuously self-reflective, and interpretive of the interviewees’ responses so that some analysis can take place within the context of the interview itself. I used these guidelines to the best of my ability in the creation and execution of my interview schedule in order to acquire the quality information that Kvale (1996) speaks of.

#### 4.2.2.3 *Conducting Interviews*

The participant interviews primarily took place in the Overberg region of the Western Cape. Two were held in Hermanus, two were held in Caledon, and one was conducted over the phone. For three of the five interviews, an interpreter accompanied me in order to properly communicate with the interviewees who felt most comfortable speaking in isiXhosa. The interviews were held in a variety of settings and organised in a fairly casual manner. It was done this way after taking cues

from the interviewees during the interview scheduling process; the interviewees tended to be very relaxed regarding the time and place of the interview so normally these details were decided on the spot. After receiving permission from the interviewee, I recorded each of the interviews so that I was able to return to the interview for future analysis. The interpreter who accompanied me worked in a very professional manner. Prior to the interviews, we discussed the issue of privacy and sensitivity. She provided an invaluable service to me and the “Just Tested for HIV” programme.

#### *4.2.2.4 Interview Reflection*

Kvale (1996) stresses the need for the interviewer to reflect on the answers provided by the interviewee as well as for the interviewer to reflect on their own thoughts and feelings during the interview process. After each interview wherein I used the interpreter, she and I discussed the nonverbal cues given by the interviewee. I appreciated and took special note of the translator’s thoughts on the subject because she was able to interact with the interviewees in their first language. Not being a Xhosa speaker left me at a disadvantage when it came to reading the interviewees body and tonal intonations but I believe the interpreter helped me fill that gap. On top of this discussion, I kept a log of my thoughts after each interview, including the two where translations were not necessary. The log improved my memory and perception of the interviews when I went back and listened to them for analysis.

I would have hoped for an Afrikaans participant as the Overberg is a primary Afrikaans speaking area. However, I received no Afrikaans participants indicated their interest in being interviewed.

As a precaution, I debriefed with someone close to me after all of my interviews. I did experience some emotionally challenging feelings about my possibly intrusive role as a researcher during this time but explaining my feelings to someone else helped me through the process.

#### *4.2.2.5 Extra Interviews*

While the basis of my research is built upon “Just Tested for HIV” programme pilot, due to timing issues, an opportunity to conduct further interviews arose late in the thesis process. With the help of Right to Care, the programme had been piloted with over 70 users. However certain circumstances resulted in Right to Care no longer being able to provide HIV testing through its mobile clinics. To ensure the continuance of “Just Tested for HIV,” my colleague Dr. Nembaware travelled to the Eastern Cape province of South Africa to officially launch the programme. She trained a group of counsellors who were responsible for counselling people during the pre and post HIV testing process. The counsellors were very enthusiastic about the programme and signed up as well. Many responded to the survey invitation SMS and I was able to conduct slightly shorter, telephone interviews with three of these counsellors. Their insight and perspective only furthered my understanding of the “Just Tested for HIV” programme. The analysis of these interviews is also included in the following chapter.

### **4.3 Research Considerations**

#### ***4.3.1 Scope***

This study only seeks to analyse the experience of participants in Cell Life’s “Just Tested for HIV” programme. For the majority of the time during which this research was conducted, the programme had only been piloted through the Right to Care mobile clinics. These mobile clinics operate primarily in the more rural parts of the Overberg region of the Western Cape; they often stop at farms, construction sites, and food processing plants. In that regard, these particular clinics do not reach an especially varied population. Right to Care did advertise the programme on their Facebook page which is a platform that anyone with the internet can access. It is unknown, however, the number of people who viewed this advertisement. One interviewee indicated that

she signed up for the “Just Tested” programme after seeing it advertised in this way. She lives in Johannesburg, South Africa.

Figure 10. Screenshot of the Right to Care Facebook page



#### 4.3.2 Limitations

There were three major limitations to this study. The first was due to the fact that mHealth is a relatively new phenomenon and therefore there is a lack of literature on mHealth programme successes and failures. The broader category of ICT4D has a larger body of literature to work from however not all ICT4D initiatives are applicable to mHealth.

Secondly, this study was limited by time. The interviews had to take place midway through the interviewees' participation in the programme due to this limitation. It is unknown whether different or further information could have been extracted from the interviews had they been conducted after the participants' completion of the programme.

Finally, I was only able to interview five participants in the programme. I had hoped to interview at least eight, but due to unforeseen circumstances, this number had to be adjusted. The reason for amount is due to an extreme drop off in new participants. At this time, we are unsure as to why people stopped signed up at the rate at which it began. We believe that Right to Care may have experienced problems with its clinic (the mobile clinic was provided by yet another organisation for Right to Care to run and that organisation is believed to be going through financial readjustments). Regardless of the reason, I received less data than I hoped I would acquire at the beginning of my study. To address this issue, however, I will be triangulating the data from my interviews with the document review as well as interviews with HIV testing counsellors.

The scope was indeed a limitation on the study. Cell Life partnered with a fairly small organisation to pilot this programme. Had they partnered with a larger organisation, their sample size for the interview pool would have presumably been larger as well. With only 70 people signed up for “Just Tested,” the chances of people responding to the survey SMS were less likely.

#### ***4.3.3 Significance***

This study attempts to add to the growing body of mHealth literature that focuses on the developing world. The rapid uptake of mobile phones on the African continent makes it a promising arena to address HIV/AIDs, an issue that affects nearly every South African in some manner. However, it is imperative that mHealth projects be adequately researched before they are offered to the public. If the public is saturated with under-researched programmes, it could potentially compromise the effectiveness of the field as a whole. Therefore, the “Just Tested for HIV” service is making a positive contribution towards thwarting this potential situation.

## **4.4 Analysis Methodology**

### ***4.4.1 Departure from the Health Belief Model***

Up until this point, the Health Belief Model had served as a central focal point in the thesis. The HBM was a useful tool during my action research. It provided theoretical justification for the “Just Tested for HIV” programme itself as well as the content in the SMSs. The six pillars of the model served as pertinent points to properly address health behaviour in people who have recently tested for HIV.

Hypothetically, the HBM could also be used in the creation of the interview schedule as well as the analysis of the data collected. As previously discussed in the methodology chapter, sensitivity to the fact that my interviewees could be affected by HIV/AIDS was a central and important concern of mine while I was constructing my interview questionnaire. For that reason, I chose to ask broad questions about the interviewees’ opinions of the “Just Tested for HIV” programme instead of using the HBM pillars to direct my interviews. There were two reasons for this decision. Firstly, because my interviews took place at a midpoint in the three month programme, not enough time had passed since the participants’ start of the programme to assess any change in their health beliefs in the ways outlined by the HBM. Secondly, the HBM uses constructs such as an individual’s “perceived severity” or “perceived susceptibility” to various health conditions in order to assess the individual’s health beliefs. Because HIV/AIDS requires a heightened level of sensitivity, I was not prepared to engage the interviewees in these topics. Also due to the relatively short amount of time that the participants had been involved with the programme, I did not expect health behaviour or belief changes to be the only measure of success for the programme at that point. Instead, I believe that the appropriate measure of success would be the overall acceptability of the programme according to the participants.

Had I decided that the HBM remained appropriate, it could have uncovered some pertinent data. Health belief modification and, further, health behaviour modification are central to the goals of the “Just Tested for HIV” programme. If the circumstances had been different, using the HBM could have been a valid and fruitful method of constructing the interviews and analysing the data. However, I will rather be employing Grounded Theory Methodology to analyse the interview data.

#### ***4.4.2 Background of Grounded Theory***

To analyse the data in my interviews, a more flexible theory was required. Grounded theory is a method of analysis developed by Barner Glaser and Anselm Strauss (Glaser and Strauss, 1967). In their book *The Discovery of Grounded Theory* (1967), Glaser and Strauss seek to provide sociological, qualitative studies with an appropriate way to analyse data that is not only valid to the academic community but also relevant to the practitioner. These methods “consist of guidelines that aid the researcher (a) to study social and psychological processes, (b) to direct data collection, (c) to manage data analysis, and (d) to develop an abstract theoretical framework that explains the studied process” (Charmaz, 2001: 675).

Within grounded theory, there are two distinct approaches to analysing qualitative interviews: constructivist and objectivist (Charmaz, 2001). I engage with my research using the former approach. In the constructivist view, methods do not guarantee objective facts about the world. Instead they claim to study how a study’s participants create ‘meanings and actions.’ “Constructionists also view data analysis as a construction that not only locates the data in time, place, culture, and context, but reflects the researcher’s thinking” (Charmaz, 2001: 677). The objectivist view, on the other hand, assumes that the data from the interviews contains hard facts about the world. The data that I gained from my interviews cannot claim to provide objective facts and each person gave their own opinion or experience of various aspects of the programme.

These opinions and experience are undoubtedly located in time, place, culture and context. I also acknowledge my own bias as a researcher, student, female, and foreign national within the context of the interviews.

#### ***4.4.3 Grounded Theory Process***

Grounded theory provides an outline as to how researchers should analyse data. The first step to doing so is through ‘open coding.’ The constructionist approach to grounded theory suggests that the researcher be reflexive when going through this process. After transcribing my recorded interviews, which allowed me to further immerse myself in my interviewees’ responses, I also went back into my personal log of immediate post interview thoughts and feelings. This process assisted me in fully engaging with my data while I asked the questions that Glaser (1978) proposes for grounded theorists to do when coding data:

1. What does the concept or code explain about the data?
2. How does the concept or code apply to the answer which the interviewee gave?
3. Where does this concept take the data in terms of explanations?

These questions allowed me to define, to the best of my ability, what was happening in the data (Charmaz, 2001) as I went through my transcriptions, line by line, to make notes of my thoughts and interpretations of the interviewee’s words.

Following the notes made with open coding, Hernandez (2009: 52) explains that the second process in classic grounded theory methodology is sorting the opening coding into what he calls “selective codes.” Selective codes are used to arrange the mass amount of open codes into more overarching themes or issues. These focused codes “are more abstract, general, and, simultaneously, analytically more incisive than many of the initial codes that they subsume”

(Charmaz, 2001: 686). This process was essential in order to synthesise the data from the interviews.

After the selective coding process, grounded theorists are encouraged to engage in “memo writing” (Charmaz, 2001: 687). Memo writing is a process which allows the researcher to use free thought to deconstruct the focused codes which arose. During memo writing the researcher is encouraged to spot any holes in the data and take then take the opportunity to re-interview participants to gain further clarity. The memos are then sorted and used in the theoretical sampling process to sharpen the concepts and deepen the analysis which ultimately leads to the creation of theory. Due to the time restrictions within this project, my use of grounded theory stops at the focused codes stage because I was unable to get the opportunity to re-interview participants or collect more data. Therefore, my grounded theory analysis will conclude with the examination of the focused coding. Although this is not ideal, Charmaz (2001: 675) clarifies that “grounded theory methods consist of flexible strategies for focusing and expediting qualitative data collection and analysis.” For this study, I capitalised on the flexibility and openness that grounded theory methodology offers.

#### ***4.4.4 Document Review***

Document review is often used in qualitative research. It functions as a “means of triangulation – ‘the combination of methodologies in the study of the same phenomenon’” (Bowen, 2009: 28). The review of documents gives legitimisation to a study in that it assists in dispelling arguments that the study comes from a single source and which may be full of the researcher’s biases. Bowen (2009:27), however, defines documents appropriate to document analysis as “documents contain[ing] text (words) and images that have been recorded without the researcher’s intervention”. The documents that I analyse, both the opt out log serviced by Dr. Nembaware, and the refusal of service log kept by the Right to Care nurses, cater to these requirements.

## **4.5 Summary**

This chapter discusses the three distinct methodological processes that were utilised in this study. First, it addresses the methodology behind a case study design. Secondly, it outlines the methods that were used in researching the “Just Tested for HIV” programme. Finally, it reviews the methodology behind analysis of the data that was collected through that research. In the next chapter I will review and analyse the findings of the research.

University of Cape Town

# Chapter 5. Findings & Analysis

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In this chapter I will present a justification for my departure from the health belief model as well as the reasoning behind rather choosing to employ grounded theory methodology for my analysis. I will first unpack grounded theory to highlight the methodological processes used in the analyses and then apply it to the interviews I conducted with the “Just Tested for HIV” programme users. I will also provide an analysis of interviews with HIV testing counsellors, as well Cell Life’s findings regarding users who chose to opt out from the programme prior to its conclusion and individuals who turned down the service after testing for HIV. The analysis will also be informed by my own observations.

Through this data and analysis I hope to answer my primary research questions. These are:

1. How is mHealth being used to address HIV/AIDS in South Africa?
2. Can mHealth programmes be successful in supporting the treatment and prevention of HIV/AIDS?
3. How was the “Just Tested for HIV” programme received by the participants?

## 5.1 Grounded Theory

The construction of the “Just Tested for HIV” programme was highly informed by the Health Belief Model. The need and justification for this model was explained previously in the literature review chapter. The HBM could also be used to conduct an analysis of the research findings. It would be beneficial to use the HBM constructs to monitor exactly how the participants’ views and habits had changed. However, due to the various reasons explained in the previous methodology chapter, asking direct questions about personal habits did not seem appropriate for the interviews

that I conducted. Therefore, it was necessary to follow a different theoretical framework during the analysis process.

I employed a variation of grounded theory analysis in order to extract the deepest meanings and information from the interviews that were conducted. Grounded theory hopes to be a “redefinition [of good science] in order to fit qualitative research and the complexities of social phenomena that they seek to understand” (Corbin and Strauss, 1990: 418). Grounded theory encourages intertwining the researcher’s observations, which can assist in recording non verbal communication, with a process of ‘coding’ the words actually used in interviews. What results are rich findings that help solve qualitative research questions. I will provide a more in depth explanation of grounded theory as well as my reasons for using grounded theory methodology in the following chapter.

Out of the interviews, five focused codes came to light. These were:

*Understanding* → data which referenced the participant’s ease of understanding in regards to the directions, content, and use of language.

*Usage* → data which focused on how the participant used the programme; whether they shared information with others, saved their information, applied the content of the SMSs to their own life, etc.

*Content* → data which described how the participant felt about the content they received in the SMSs. What were their feelings / likes / dislikes / trust of the content / knowledge

*Programme Logic* → data which highlighted how the user experienced different programme functions such as the process of signing up, the frequency of the SMSs, the time the SMSs came, etc.

*Privacy* → data which was in reference to how the user viewed privacy in regards to the content and the way in which the content was disseminated (SMS).

## **5.2 Analysis of Focused Codes**

I will now unpack and analyse each of the focused codes that emerged from the participant interviews.

### **5.2.1 Understanding**

The ability for participants to understand the intent, directions, and content itself was a vital component towards the success of the “Just Tested for HIV” programme. If participants did not properly understand the marketing material, which included the posters and pamphlets positioned at each testing location as well as the directions or encouragement from the nurses, they may not feel inclined to sign up. Having an incorrect notion of what to expect could lead to users feeling dissatisfied or deceived which would have a negative effect on programme success. Advertising the programme as clearly as possible was a priority during the programme.

Over half of the interviewees (three out of the five interviewees) reported that they did not have a full understanding of the programme before it started. These participants did report, however, that they soon came to understand the programme after receiving the first few messages. It should be explained that the interviewee quotes which read in the third person tone are that way because it is the exact wording of the translator.

This woman understood the sign up procedure but was unaware of what she should expect:

*“She said that the paper only stated that if you are HIV positive then you can SMS and if you’re not then SMS that number. And she only understood when she started to receive the SMSs”*

This participant had similar sentiments:

*“He says the paper was not clear but then they told him that if you send the SMS then the SMSs will tell you clearly what’s going on.”*

The other two interviewees reported that the SMSs were as they expected them to be, indicating that the programme was sufficiently advertised in the pamphlets distributed:

*“Yeah, definitely they are what I was expecting - Just to know more about the HIV virus.”*

One piece of information which stood out was that none of the users reported that the nurse (at the clinic where they had received the “Just Tested for HIV” pamphlet) explained the programme in detail.

Language was another point of importance in the creation of the programme. Although some SMSs contained medical information, the intent was to have the messages read in the most approachable and readable manner. Because neither Dr. Nembaware nor I spoke fluent isiXhosa or Afrikaans, a translation service was used to translate the SMSs. Determining whether users felt comfortable with the language was a goal of this research.

Three out of the five interviewees indicated that the language used in their SMSs was clear and easy to understand:

*“She says that the ones that she’s been receiving, they are not that difficult to her. Because she understands them.”*

One interviewee, whose native tongue was Zulu reported that the Xhosa in his SMSs was “*killing him*.” One woman, in her early 20s, indicated that the Xhosa that was used in the SMSs was very “*old*” and “*too deep*” for her to understand. She reported that a different Xhosa was used by the

young people. Although the needs assessment which was performed before the “Just Tested for HIV” pilot launch indicated that isiXhosa, Afrikaans, and English were the most prevalent languages in the region of the pilot, language diversity is a principal issue in the South African context. This point is clearly demonstrated by the frustrations of the first language Zulu speaker.

### *5.2.2 Usage*

The interviews revealed some significant information in terms of how the user interacted with the meaning of the message as well as the SMS form in which the messages were sent.

All of the interviewees indicated that they kept the SMSs on their phone for as long as possible. Some needed to eventually delete them to free up space on their phones but two reported that they still had the SMSs stored. The fact that the users wished to keep their SMSs for as long as possible indicates that the transmission of information via SMS as opposed to other media methods (such as radio, television, or print) encompasses unique qualities that may make the SMS method more effective than the others. SMSs allow users to retain the physical message for as long as they desire, enabling them to return to the content as many times as they need. This quality is not available to the user when information is transmitted through other media methods. While printed information such as booklets or pamphlets would also allow the users to keep physical copies of the information, the intrinsic privacy of the cell phone and therefore the SMS allow users to access the information in the most private and confidential manner.

The interviewees indicated their liking for the programme itself through their admission that they shared the information they received with close people in their lives. All five of the participants indicated that they talked to close friends and family about the information they received. More than one interviewee indicated that they encouraged friends to also sign up.

*“I got a friend that friend, she’s also HIV positive, I told her to send a Please-Call”*

Each of the interviewees, in their own manner, expressed how the SMSs had affected their outlook or behaviour. Because health behaviour change was not possible to measure at the time of the interviews, attitude or outlook change held great weight in determining the current success of the pilot. Most of the interviewees had overwhelmingly positive reactions to the programme and expressed how it had affected their lives.

*“[The SMSs] have changed her life, these SMSs. Because after she found out that she has the virus she thought that she was going to die and all those things but now she has hope that she’s going to live a long and better life.”*

*“[The SMSs] just help me have a positive life...they just motivate me”*

*“Because what the SMSs are saying: he sees them through other people. Like he sees what other people are going through and then what they relate to other people and then he says that maybe one day it will happen to him so the SMSs really speak to him.”*

The length of time and desire to keep the SMSs on their phones as well as the positive affect that programme participation had on the interviewees’ outlooks indicated that these users interacted with the SMSs in a very positive and personal manner. Such interaction is an optimistic indicator for future success.

### **5.2.3 Content**

Another indicator that can be used in measuring programme success is the user’s reaction and feelings towards the content of the SMSs. The simple question of whether or not the user liked

what they received has huge implications towards the overall affect that this programme might produce. Similarly to 'usage,' the users' feelings towards the content is an important indicator especially at this time when measuring health behaviour change was not an option.

Four out of the five interviewees indicated that they liked the SMSs. One woman indicated that the SMSs didn't make her feel as though she was somehow different because of her HIV:

*"They are making her feel comfortable; like see her as everybody else. She looks at her, and sees her. Like, more like everybody else. They don't look at her differently."*

The SMSs that covered the topic of living life in a healthy manner and sticking to one partner at a time seemed to be the most popular. When asked if they had a favourite topic that the SMSs covered, these were some of the responses given:

*"He says that the one that he likes, it's the one that says that you should have one partner and then if you have that partner before you commit into having sex then you should go and get tested first."*

*"There is one that states that if you are HIV positive you have to stick to one partner, you know. You have to be serious about your life, you know. And use a condom. All the time."*

*"He says it's the message that tells you should keep yourself, you should protect yourself, don't think that just because you're HIV negative, don't think that you are free. Keep on protecting yourself."*

Only one interviewee reported a least likeable SMS. He felt that there was too much emphasis on sex and condom use. He did not have a partner at that time and felt overwhelmed by the way the SMSs prominently featured sex topics:

*“Use a condom. Use a condom. All day. I don’t have a partner right now. So I said no, I have to stop [the SMSs].”*

Though this programme stems from testing for HIV, this interviewee’s comments serve as pertinent advice. “Just Tested for HIV” intended to stand out because of the fact that it offers a line of SMSs intended for people who have tested for HIV with negative results. The goals of the ‘negative’ SMSs are to encourage continued or improved positive health behaviour, to reduce the stigma around HIV, and also to motivate those people to retest after a three month window period is up. However, over-emphasising HIV and sex may offend or discourage users who are not very sexually active, such as the case of the man previously mentioned. While focussing on HIV in the ‘positive’ SMSs is likely to be accepted, the ‘negative’ line may need to diversify its topics to prevent alienating users. Diversifying the topics would not take away from any of the goals of those SMSs.

Trustworthiness was the final indicator sought in determining the interviewees’ feelings about the SMS content. All of the interviewees reported that they found the content trustworthy. While this affirms the programme itself, it also underscores the need for research and sensitivity in HIV related SMS based programmes. Being a trusted source of health information is a privilege that requires careful consideration.

#### **5.2.4 Programme Logic**

The programme logic code summarised the operational factors which drove the “Just Tested for HIV” programme. These factors included the process for signing up and the frequency and timing of the SMSs. The acceptance and success of these operational processes are capable indicators of the programme’s reception as well.

Out of the five interviewees, three people signed up for the programme when the Right to Care mobile clinic visited their place of work; each of these people works on farms in the Hermanus / Caledon area. Another interviewee stopped at a mobile clinic she saw on her own accord. Out of these interviewees who signed up for the “Just Tested for HIV” programme, all of them reported that they were not encouraged by a nurse to sign up. Only one of these four people reported that a nurse briefly explained the programme to them. The programme was not designed to work like this; instead the Right to Care nurses and/or counsellors were intended to explain and promote the programme after each individual tested for HIV at their clinic.

The final interviewee, who did not sign up at a mobile clinic, reported that she signed up after she saw a post about the programme on the Right to Care Facebook page. Right to Care is very involved on the social networking site; they have many “friends” who follow their posts. This woman was “friends” with Right to Care and decided to sign up for the “Just Tested for HIV” programme. While this cannot be the primary source of advertisement, popular social networking sites could be potentially prosperous in gaining new users.

Each interviewee reported that 5 PM was a good time to receive the SMS. Four out of five interviewees indicated that they enjoyed getting an SMS each day:

*“She says she doesn’t mind when she gets the SMS [everyday] as long as she gets the SMS because she enjoys reading them.”*

Four out of the five interviewees also reported that they would prefer if the programme lasted longer than three months. One woman said that she was fine with the programme ending after three months as long as “*they’re going to start again.*” Others reported:

*“Yeah I just wish they were much longer than 3 months because when I read that message that said just the 3 months, I just wish it could be a little bit longer.”*

*“He’d like them to continue longer.”*

*“For longer. For longer would be good.”*

With the exception of nurse explanations, the operational procedures that determine the success of the “Just Tested for HIV” programme were well accepted. Although the interviewees reported that they would prefer the programme

### **5.2.5 Privacy**

Although cell phone design carries a certain amount of inherent privacy, there are still factors that make the user to SMS based HIV programmes more vulnerable than those exposed to interventions which employ different media methods. While radio, TV, and billboards can reach users without leaving traceable evidence of doing so, cell phone SMSs stay with each user (should they choose not to delete them). As researchers we were aware that concrete traceability could be problematic in that difficulties may arise if the privacy of one’s cell phone is breached. These are weighty scenarios, especially for topics that require the amount of sensitivity as HIV/AIDS.

Each interviewee indicated that they owned a personal cell phone. Despite the concerns previously mentioned, only one interviewee reported having worries about whether someone might see the SMSs on his phone; he reported that he was most worried about someone from his church seeing the SMSs:

*“You see as a Christian, I am a representative. If they see [the SMSs] they say, SMS HIV how come you, why do you receive?”*

*“He says that he doesn’t mind but that if a person from church would ask how come these SMSs of HIV and AIDS but if it’s someone else then he doesn’t mind.”*

One of the goals of the “Just Tested for HIV” programme is to reduce the stigma around HIV/AIDS. Speaking about the disease, sharing information, and encouraging understanding and knowledge can contribute to the reduction of stigma (Skinner, 2004). However, it is important to remember in addressing stigma that it is indeed still very present (ibid). This man’s concern over whether people from his church would read the SMSs holds a great deal of validity. In the creation of the content for “Just Tested for HIV,” the words HIV and AIDS were purposely kept at a minimum because of the associated stigma. This was done despite the fact that the needs assessment revealed that most people were comfortable with those words being used. Regardless, this interviewee’s concern serves as a reminder for the sensitivity required.

Three out of five interviewees said they would not mind having someone see (accidentally or otherwise) the SMSs on their phone because they could then start a conversation and the person might learn something:

*“She says that she doesn’t mind because maybe there’s something that the person will learn from the SMSs so she doesn’t mind if someone sees them.”*

*“He says that he wouldn’t mind because maybe the person would find the knowledge in the SMSs and then he would learn something. He would really like it if someone would see them.”*

*“My friends like joking around so maybe they would joke around about the SMS but then we could start a conversation about, “Yoh, HIV, I’m scared of testing” and because they scared. Really, they’re scared. So maybe they would start a conversation on the SMSs and it would be like a discussion and stuff. So that’s how my friends would react. When they saw the SMSs.”*

These three responses indicated a very positive response not only to the programme but also to the SMS format as well. These interviewees confirmed that the SMS format is conducive for sensitive information. They reported that if their cell phones with the programme SMSs were exposed, it would not be a problem. While this may be one sided, it can be mentioned that for anyone who feels uneasy about the SMSs, they are able to delete them at any point.

The final interviewee reported that she did feel there was any threat of her phone being stolen or examined by others.

### **5.2.6 Overall Likeability**

While most of the interviewees, the programme participants and the counsellors, touched on various ways that the programme could be improved, the general over-arching impression was that the programme was received very well. In the participant interviews, I asked why they had felt the inclination to respond to the interview offer. The answers given are indicative of their general feelings and acceptance of the programme:

*“She said that she received an SMS saying that they are people there is going to be interviews seeing that people how are they receiving these SMS and then she says that she wants to make sure that she wasn’t playing around - She was serious about these SMSs, this programme.”*

*“He says that firstly he was interested in the SMSs and then they gave him the knowledge that he needed and then he thought maybe he’s going to get even more today.”*

*“I don’t know, actually. I just wanted to take part in something good.”*

There was a sincere honesty that came from each of these participants when they gave these responses. Based on my interviews with the participants, the programme is accepted very well.

Counsellor acceptance was also important. Even more so than the participants, the counsellors that I spoke to seemed genuinely enthused and confident in the programme and its future success.

One woman told me that:

*“I love the SMSs you are sending me because for me they are giving me strength to do my work.”*

Another counsellor enquired whether and when Cell Life could create a similar programme for people with diabetes and other infections. His confidence in the “Just Tested for HIV” programme led to his certainty that people with other conditions would also benefit from similar programmes.

## **5.3 Extra Interviews**

### ***5.3.1 Eastern Cape HIV Testing Counsellors***

As mentioned in the previous chapter, I had an opportunity late into the research process which allowed me to interview HIV testing counsellors who are based in the Eastern Cape and part of the beginnings of the official “Just Tested for HIV” programme (as opposed to the pilot which took place in the Western Cape). These interviews were more unstructured in nature, a quality

likely resulting from the fact that they were done over the phone, and slightly less extensive than the interviews done with the participants. The counsellors provided invaluable insight and depth that I would not have had without them. While they give perspective from a different side, their addition to my research held special gravity in that all three disclosed on their own accord that they were HIV positive as well. Each of the counsellors described their line of work; this woman summed up the position succinctly:

*“I’m doing counselling. I’m HIV positive. I’m doing HCT testing which is we test our patients for HIV, not just patients; we test anyone who wants do to an HIV test. And then we do debrief counselling, in-going counselling, and then we do the ongoing counselling to understand if people are positive or already on ART. And then I do adherence counselling to those who are on ARTs and I do in court counselling while they are waiting for the doctor or waiting for their medication.”*

The counsellors’ in-depth involvement in the patients’ experience makes their ‘buy-in’ a fortuitous addition to the programme. After analysing the counsellor interviews, various themes became apparent. Firstly, the counsellors interviewed had overwhelmingly positive feelings towards the programme. Each of them reported that they had purchased a notebook in which they write down the SMSs that they receive. The counsellors told me that they go back to re-read the SMSs not only in their phones but also in these books. As they spoke about the SMSs and their books, the counsellors’ enthusiasm was palpable.

*“All the messages that you send me, I wrote it down. All of them. Every message that you sent me I write it down and I write it down all of them.”*

*“The SMSs I got from you guys I wrote in a special book for me so that I can learn them, some of the language. It’s so refreshing.”*

One counsellor gave validation for using SMSs as a way to transmit information as opposed to the more traditional forms of media that have been used for HIV interventions in the past:

*“They [the SMSs] are good, they are very good. And also people learn something about this. You know that the problem is this, they don’t want to hear anything from the radios or TV, you know, when he get this message, he gets this message, if he wants he can get these messages.”*

The counsellor reiterated the positive attributes of the SMSs. When explaining that “they don’t want to hear anything from the radios or TV,” this counsellor shed light onto his patients’ preferred form of media. Messages via television or radio can often go ignored because they are aimed at the general population. There is no way to know if people are tuning in or paying attention when the messages are transmitted in such a manner. Using cell phone technology however, people “get the message” and they do so because they want to. They are prepared to receive the message, prepared to read it, and, because the SMSs are sent directly to the individual, it is more likely that they will absorb this information.

Another counsellor illustrated the need for counsellor or nurse ‘buy-in’ for the programme to work. The interviewees from the pilot phase reported that they were generally not encouraged by a nurse or counsellor to sign up and that they had done so on their own accord. It is safe to say that these people were self-motivated enough to explore new options for information. The counsellors in the programme launch in the Eastern Cape should be able to attract other people who would have not been interested or motivated to join otherwise:

*“It’s helping me a lot. It’s helping me a lot. Even the person that I give them the number to, they come back to me and they show me their thoughts on you guys.”*

*“Yes. About the programme. Even the patients are already that are already HIV they are excited about it. Because we do encourage them, yes.”*

*“And even to talk every day with the patients. Even those who don’t understand the sickness. There are SMSs there for them so they can read them and make them understand they are not alone in this world. There are people for help. They need help.”*

The general insight provided by the three counsellors was one of appreciation and support for the “Just Tested for HIV” programme; and that this sentiment was also replicated in their patients. There is no doubt that the counsellor support lead to more patients being involved and experiencing the programme.

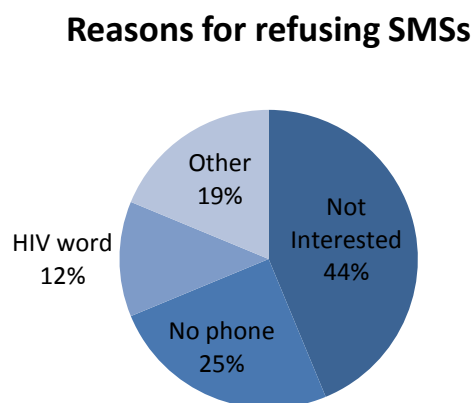
#### **5.4 Document Analysis**

As mentioned in the Methodology chapter, the final component of my findings comes from document analysis. I have reviewed and analysed two different documents. The first is a nurse “refusal log.” During the initial meetings with Right to Care, the nurses for the mobile clinics were asked to keep a refusal log in which they could document why individuals were declining the “Just Tested for HIV” service. This request was made so that an individual’s reasons for being opposed to the programme could be taken into consideration after the conclusion of the pilot and before the launching of the full scale version. The second document is a log kept by Dr. Nembaware in which she recorded the reasons people had for choosing to opt out of the programme before its completion date. Both of these documents may provide insight into the level of validity and acceptance that SMS based, HIV focused programmes have in South Africa.

### 5.4.1 Nurse Refusal Logs

During the pilot programme, the nurses who worked in the Right to Care mobile clinics were asked to keep records of why patients were uninterested in joining the “Just Tested for HIV” programme. However, consistent to the patient interviews which described a lack of nurse involvement, the refusal log was only kept for the first week of the programme pilot. Regardless, the information that was collected does provide useful information for programmes such as these. The following chart outlines the recorded reasons people gave for refusing the “Just Tested for HIV” programme.

Figure 11. Reasons why individuals refused the “Just Tested for HIV” service. Reproduced from Nembaware (2012)



Slightly less than half of those patients who refused the service were simply uninterested. 12% refused the programme because they reportedly did not want to receive SMSs with “HIV words” such as HIV, AIDS, or other related terms. This 12% highlights an important issue that is present in today’s South Africa. The level of distress that these words cause alludes to the bigger issues of stigma, denial, and disassociation.

25% of those that refused the service did so because they did not own a personal cell phone. This may be the most alarming information that the refusal log provides; it draws attention to one of the major pitfalls of mHealth which is the fact that it is unable to provide service for the most vulnerable. While cell phones are growing more prevalent at all incomes levels, there are still many people without their own private access. If it is assumed that these people do not possess cell phones due to financial limitations at a time when cell phone access is seen to be affordable across the income spectrum, then it is likely that these people may constitute some of the most marginalised. The sharing of cell phones is often a solution for people and communities unable to afford individual access and this system has its benefits. Kaplan (2006: 10) explains that “Shared use in some locations could be an important constraint if mobile phones are to be used to convey health information since two-way communication in a shared system is difficult as a non-owning user can make outgoing calls but cannot receive spontaneous calls. SMS text messages, if not deleted, can be observed by subsequent users” (14). This is an issue that mHealth programmes inherently cannot avoid; the “Just Tested for HIV” programme is unable to escape this criticism as well.

#### ***5.4.2 Programme Opt Out Logs***

Dr. Nembaware kept a record of the reasons why individuals who chose to end their participation in the “Just Tested for HIV” programme did so. The Communicate system (described in the Methodology chapter) keeps track of the phone numbers of programme participants who choose to opt out of any of Cell Life’s interventions. It also provides the date they began the programme and the date they chose to end early.

While I was given the option to phone more of the users who decided to opt out, I decided against it. The decision was made to respect the user’s choice to be done with the programme. Because “Just Tested for HIV” deals with sensitive subjects, it is important that users feel safe and

comfortable providing their phone numbers. I decided that I did not want to risk the programme's integrity by calling the users who opted out early as that may provoke feelings of distrust or ill will towards the programme.

However, I did have access to the opt out log kept by Dr. Nembaware of programme users from the pilot phase which revealed interesting information. At the time the log was kept, 22 users had sent a PCM that indicated that they would like to opt out of the programme. Of these 22 users, Dr. Nembaware was able to reach 17 people. Of these 17, only two users confirmed that they wanted to opt out. The 15 others had various reasons for sending the PCM which resulted in two main themes.

Language trouble was the most common reason for users choosing to opt out. One participant indicated that the messages she was receiving in isiXhosa were too high level. This could indicate an inconsistency within the language depending on age group or region. After speaking with Dr. Nembaware, the user decided to opt back into the programme and to receive the English messages. Another user had a similar experience; although in that case they had signed up for the English messages when they would have been more suited for isiXhosa. To address this issue, a change was made to the advertisement pamphlets after the pilot phase completed. There remained three versions of the pamphlet, each in one of the languages offered, however all three pamphlets contained the opt-in numbers for each language. For example English pamphlets read:

*To receive SMSs in English, send a PCM to xxx-xxx-xxxx*

*To receive SMSs in Afrikaans, send a PCM to xxx-xxx-xxxx*

*To receive SMSs in isiXhosa, send a PCM to xxx-xxx-xxxx*

The second issue was that users were under the impression that they would be charged for the service. After reiterating that the programme was indeed free of cost to the user, they requested to

be opted back in to the programme. To address this issue after the pilot's conclusion, users were reminded in SMSs as well as in the advertisement pamphlets that the programme was absolutely free to the participants.

## **5.5 Summary**

To analyse the interview portion of my data, I employed a modified version of grounded theory. The grounded theory process allowed me to immerse myself in the qualitative data which in turn produced sensitive and quality analysis (Glaser 1978). This analysis, as well as document review and my own observation, allowed me to answer the main research questions which are listed at the beginning of the chapter.

Firstly, how is mHealth being used to address HIV/AIDS in South Africa? The literature review chapter provided baseline examples of how mHealth had been used in South Africa in the past. The experience I had working with Cell Life afforded me an in depth view of how this organisation is utilising mHealth in particular. While the "Just Tested for HIV" programme is just one example of a South African based mHealth programme, it allows us to understand the current level of mHealth and to envision what could become. This mHealth programme addresses HIV/AIDS in more ways than one. An important quality that separates the "Just Tested for HIV" project from others is that it offers support and information to individuals who are HIV negative. At a recent ICT4Health conference, Professor Yunkap Kwankam (ICT4Health, 2012), the CEO of Global eHealth Consultants based in Geneva, commented that the current state of eHealth had been limited to "reactionary" programmes that address disease. Kwankam suggested that the way forward was to create programmes that "produced health" in addition to the ones that addressed disease. The option of receiving HIV negative SMSs in "Just Tested for HIV" leans towards the type of preventative care of which Kwankam spoke. In this way, the "Just Tested for HIV"

programme provides evidence that mHealth is being used as a support system and to disseminate knowledge for people directly and indirectly affected by the disease.

Secondly, can mHealth programmes be successful in addressing HIV/AIDS? Again, my research was based solely upon the “Just Tested for HIV” programme. As I stated previously in this chapter, because of the timing of the midway assessment, the only appropriate measure of programme success at this time would be the overall acceptability of the programme according to the participants. Due to this condition, answering this research question requires addressing the third and final question which is how was the “Just Tested for HIV” programme received by its participants?

As mentioned previously, during each participant interview, I asked why they felt inclined to participate in the interview. The answers that I received to that question ultimately answer the final research question too. Programme users were for the most part adamantly supportive of the “Just Tested for HIV” intervention. Additionally, the interviews with the HIV testing counsellors affirmed this notion that, in terms of acceptability, “Just Tested for HIV” is a success.

It was my understanding that the sampling methods used could lead to skewed results as the participant interviewees were not only individuals who had decided to sign up for the programme but were also proactive enough to want to participate in an interview. To balance the results, I used the information from the participant opt out logs. However, even the majority of those people wanted to remain in the programme and had positive things to say about the SMSs.

The “Just Tested for HIV” programme illustrates the way in which mHealth is being used to address HIV and in a manner which is successful and accepted by its users. Despite its success, the data revealed ways in which this programme could be improved. Such information is

important to “Just Tested for HIV” and future mHealth initiatives. These points of improvement are discussed in the following recommendations and conclusion chapter.

# Chapter 6. Conclusion & Recommendations

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## 6.1 Conclusion

The research done on the “Just Tested for HIV” programme yielded applicable and potentially important results. Analysis of the in depth interviews, document review, and my observations as a researcher resulted in the emergence of reoccurring themes in terms of the “Just Tested for HIV” programme user experience. Privacy, programme logic, acceptance of content, usage, and level of understanding all influenced the users’ experience with the SMS based programme.

The data revealed some points where the programme could be modified; these will be discussed in the following recommendations sections. However, because of its theoretical basis, we were confident in the design of the “Just Tested for HIV” programme. The Health Belief Model, with its six critical constructs, was a major driver in the programme creation. This model was explicitly chosen in order to address the common criticism that mHealth programmes lack theoretical grounding. The hope was that if “Just Tested for HIV” saw success, that other mHealth initiatives would be able to utilise the programme design for further research and the creation of new programmes.

The “Just Tested for HIV” programme is an excellent example of the recent merge of Information Communication Technology and social development. With cell phone use on the African continent being as prevalent as it is, it is one of the most opportune forms of technology to utilise. While a range of social issues can be addressed through ICT4D, the HIV/AIDS crisis is particularly pressing, especially in South Africa.

The “Just Tested for HIV” programme is addressing this crisis in an innovative and capable manner. However, as mentioned previously, the programme could be strengthened with the modification of a few issues. It is my hope that future mHealth programmes can use these points of improvement in their creation processes. The following section contains recommendations that are specific to the “Just Tested for HIV” programme but can ultimately be applied to the greater mHealth field.

## **6.2 Recommendations**

After analysis, the data revealed a few areas where the “Just Tested for HIV” programme can be improved. The majority of data came from the participant interviews. These provided insight and knowledge that would have otherwise gone unheard.

There was only one participant interviewee who was not overwhelmingly positive about the programme. This man was receiving the HIV negative SMSs and disclosed that he was practicing celibacy at the moment. He expressed that he felt that there was too much emphasis on sex and HIV. For the negative SMS set, it might be beneficial to focus more on general health and body awareness as opposed to HIV specific issues. The emphasis on HIV and sex could be alienating and off-putting to some people as it was to this participant. Additionally, to be considered ‘pro-health’ as opposed to ‘anti-disease,’ the SMSs must feature health positive topics which does always relate back to the HIV virus.

As evidenced by the successful implementation of the “Just Tested for HIV” programme in the Eastern Cape, counsellor or nurse buy-in is integral to the programme’s success. The unexplained rapid drop off in participant sign up rates during the pilot phase may likely be contributed to the lack of nurse support; the fact that the refusal of service log was only kept for one week is

evidence of this. Such a situation contrasts starkly with the counsellor enthusiasm seen in the Eastern Cape launch. The comparison highlights the weight of this issue. To remedy the situation, any HIV testing clinic which offers the “Just Tested for HIV” programme should provide its nurses and counsellors a rigorous course on advertising the programme, the programme’s content, and the reasons for its importance. Such a course could guarantee a better rate of ‘nurse/counsellor buy-in’ and therefore improved chance of overall programme success.

Additionally, some of the counsellors and participants conveyed various adjustments or additions that they would like to see. Overwhelmingly, both participants and counsellors expressed their desire for the programme to run longer than three months; they often reported that six months would be better. If budgeting allows for it and it is a user demand, extending the length of “Just Tested for HIV” would result in having a greater positive impact. While it is understood that the three month time frame was decided upon due to the ‘window period’ in HIV testing, SMSs encouraging a retest would still be possible even with a longer overall programme length.

Desired additional SMS content was also provided in the interviews. One HIV positive woman reported that she wasn’t sure whether her child should drink from her glass and that she wished the SMS would cover this. This is an apt example of ‘untruths’ that could also be covered. Another woman asked for more information about ARV use and “more facts” about the virus in general.

Finally, it should be emphasised that the participants interviewed seemed to have blind faith in the information they were receiving. They all reported that they trusted the SMS content but could not explain exactly why; they were for the most part unaware of where the information may be coming from. For the sake of transparency and participants’ knowledge, it may be useful to

supply an SMS which explains why Cell Life, or any other mHealth developer, should be trusted as an authority on health and HIV/AIDS.

As mentioned in chapter three, action research is a cyclical process (see figure 5). The findings chapter, as well as these recommendations serve as the reflection portion of the cycle. However, due to the scope of this research, I can only put out my findings in hope that they will be used for further programme planning. In this regard, I hope that this study inspires further and more extensive mHealth research.

In tracing the path of development and the logical movements which led to the merger of ICT and development as well as explaining the specifically African necessity and use of cell phones, I hoped to place mHealth in South Africa in an understandable context. And in describing the exciting projects that are in motion, acknowledge that this field has not yet reached its full potential, which could have incredible effects.

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## Appendix A: Needs Assessment – “Just Tested for HIV” programme

*Needs Assessment : Just Tested For HIV*



### BASELINE QUESTIONNAIRE

*(English)*

**Title of the study**  
**The Just Tested for HIV Services**

**Conducted by**  
**Cell-Life**  
**South Africa**

**Funded by**  
**The VodaCom Foundation**

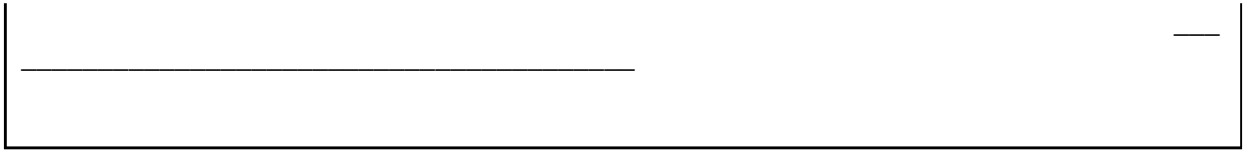
**INSTRUCTIONS: This form is to be completed by the study personnel together.**

**Date of Interview**

D	D	M	M	Y	Y	Y	Y
---	---	---	---	---	---	---	---

**Facility/Location Name**

**Interviewer Name**



## Survey Information

Introduce yourself and Cell-Life.

Describe Just Tested for HIV and what it aims to do etc.

Ask the participant if they would not mind helping us structure the Just Tested for HIV intervention; (Soon to be implemented)

Thank you for agreeing to participate in this survey. I am going to ask you some questions now and this will only take about 5 minutes.

<b>Gender</b> <i>(Please circle)</i>	Male	Female		
<b>Home Language</b> <i>(Please circle)</i>	English	Afrikaans	isiXhosa	
<b>Are you employed?</b> <i>(Please circle)</i>	Employed / self-employed	Unemployed	Part-time	Student
<b>Level of education:</b>	<input type="text"/>			
<b>school grade completed</b>	<input type="text"/>			<b>Last</b>
<b>r-matric qualifications</b>	<input type="text"/>			<b>Afte</b>
<b>Do you own a cellphone? Probes: phone sharing, privacy etc, SMSs? Please-call-mes</b>	<hr/>			
<b>When was the last time you tested for HIV?</b>	<hr/>			
<b>When you last tested, what sort of questions were not addressed in the counselling sessions?</b>	<hr/>			
<b>Would you be interested in receiving SMSs to support and inform you after testing for HIV and AIDS?</b>	<hr/>			
<p><b>Show them the marketing material..</b>  <b>Probe to see whether they understand exactly what the posters &amp; pamphlets say.</b>  <b>Ask them to follow instructions and to sign-up</b>  <b>Have you ever signed by for SMSs that inform/educate about HIV and AIDS? (Get details if it's a yes) did they learn anything? Feelings about this etc.</b></p>				

---

**Do you have any privacy concerns about this service?**

---

**What would the most ideal time to receive the SMSs be for you?**

**How many SMSs would you prefer per day/week/month?**

---

**Duration of the SMSs?**

---

**Language?**

---

**Content? Information that they would expect etc ?**

---

**Do you have problems with messages that have words like HIV and AIDs in them ?**

---

**Do you have any other concerns or suggestions ?**

---

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## Appendix B: Transcript of a Participant Interview

### Transcription #1

Researcher  
Translator  
Interviewee

*I just wanted to say thank you again for coming and then..do you have any questions before we start?*

**No, she doesn't have.**

*Okay. What year were you born?*

**Translations. 1983.**

*And where are you from?*

Eastern Cape.

*Where do you stay now?*

**Translations.** Interviewee reply.

**In Xoliswe. The township.**

*And does anybody live with you?*

My husband.

*Do you guys have any kids?*

One.

*How old?*

8 years old.

*8. Boy or girl?*

Boy.

*That must be fun. What do you do for work?*

**Translations.** Interviewee reply.

**She's working on a farm. La Vierge. The name of the farm is La Vierge; it's wine. They make wine. She picks the grapes there. They pick out the grapes, for quality.**

*How far is that from here?*

**Translations.** Interviewee reply.

30 minutes.

*Where did you sign up for the SMSs?*

**Translations.** Interviewee reply.

**At her work, every month they come and test them for HIV so she didn't test because she'd already tested. And then she took that paper and that's where she got the number for the SMSs.**

*Great. Did a nurse tell you about the SMSs or did you only see the pamphlet or poster?*

**Translations.** Interviewee reply.

**She saw a paper that has the number. That if you want to stop them the SMSs, you call the number.**

*Right. And was the paper clear? Was everything easy to understand?*

**Translations.** Interviewee reply.

**She said that the paper only stated that if you are HIV pos then you can SMS and if you're not then SMS that number. And she only understood when she started to receive the SMSs**

*Okay. What did you expect when you signed up? What were you thinking they were going to be like? Did you have any expectations?*

**Translations.** Interviewee reply.

**She said she is not finding it yet because as she has cancer so she doesn't get the advice for her, you know. She's not finding them yet.**

*And was she expecting to get advice about cancer, did you say? Were you hoping for advice on cancer?*

(Nods head yes).

*Okay. Well, so far, what do you think about them? Do you like them? Do you not like them? What do you think?*

**Translations.** Interviewee reply.

**The messages are fine because they are encouraging her. You know, they are telling her. They are telling her. They are making her feel comfortable; like see her as everybody else. She looks at her, and sees her. Like, more like everybody else. They don't look at her differently.**

*If you can remember, do you have a favorite SMS or do you like particular ones the most?*

**Translations.** Interviewee reply.

**She says that there is one that states that if you are HIV pos you have to stick to one partner, you know. You have to be serious about your life, you know. And use a condom. All the time.**

*And you like those ones?*

Yes.

*Why do you like them? Are they inspiring to you? Why do you like those ones the best?*

**Translations.** Interviewee reply.

**She says that yeah, because they are spot on the SMSs because they tell you that if you are HIV positive you don't have to drink and you have to love your life. You have to life well. Because as her, you know, she has a sister who has like the virus and then she uh woe up in the hospital because she wasn't taking care of herself. She was up and doing all the stuff, drinking and stuff. She wasn't taking good care of herself and her health.**

*Are there any SMSs that you didn't like? Or particular ones that you just don't feel good about? Or that you would like to be changed?*

**Translations.** Interviewee reply.

**The SMSs they are fine. She doesn't want to anything to.. change.**

*Really? You can tell me if you don't like them. It's okay.*

-laughter-

*And what do you do..the SMSs come every day around 5. What do you do when you get them? Do you read it right away or do you save it for later?*

**Translations.** Interviewee reply.

**She says that she reads them later on. At work she receives them later. And she receives one SMS a week?**

*Right. Because it goes down. The first 30 days was once per day and then after that it's once per week.*

**Translations.** Okay.

*But, do you like them once a day? Or how often would you like to see them because I'm not sure.. some people think maybe once a day is too much, some people think once a week is too little. What is..what do you like?*

**Translations.** Interviewee reply.

**She says she doesn't mind when she gets the SMS as long as she gets the SMS because she enjoys reading them.**

*Good, good. Do you keep them on your phone or do you delete them?*

-indicates that's she keeps them-

*That's nice. Do you read them over, like again? Or just once?*

**Translations.** Interviewee reply.

**She says she wants to read them; she can read them anytime. And she does read them. Repeatedly.**

*Good, and do you trust the SMS? Do you feel like they..when you read them, they come from a good source and you feel comfortable with them? And also why do you trust them?*

**Translations.** Interviewee reply.

**She says that while she reads them but she's not sure who they come from because they told her that people from Vodacom are sending the SMSs; she doesn't know who exactly is sending them.**

*Maybe we should tell her..yeah, it's not Vodacom. It's an organization called Cell Life and they specialize in making these programmes for health issues. This one is HIV related but they also make ones for TB and they're working on one for anti smoking. So, they are experienced in the health field.*

**Translations.** Interviewee reply.

Okay

*And where else do you get information about health or HIV? Where else do you get your information?*

**Translations.** Interviewee reply.

**If she has something that she doesn't understand or she falls down or something she goes to the counseling at the clinic. She gets the information there.**

*Okay, so the clinic and SMSs together? Okay. And do you share the SMSs with other people?*

Yeah.

*Who do you share them with?*

**Translations.** Interviewee reply.

**Some other women that she works with. She shares the SMSs with them.**

*And have you learned anything new from these SMSs?*

**Translations.** Interviewee reply.

**No.**

*So it's all things you knew before?*

Yes.

*And you like hearing it again?*

Yes.

*Okay. And would you recommend the SMSs to a friend? Would you recommend that they receive them as well?*

**Translations.** Interviewee reply.

**Yeah she has already recommended them to the friends..some of them are receiving them as well.**

*Oh good. Thank you. And how do you apply the information in the SMSs to your life. Like has it changed the way you behave or the way you think or..how does it affect your life?*

**Translations.** Interviewee reply.

**They have changed her life, these SMSs. Because after she found out that she has the virus she thought that she was going to die and all those things but now she has the hope that she's going to live a long and better life.**

*And that helps you get through it?*

Yeah.

*Good. When you first found out, it was sort of shocking..and then your feelings changed with the SMSs..is that sort of what you feel like?*

**Translations.** Interviewee reply.

Yeah.

*Are there any questions that you have that you wish were addressed in the SMSs that haven't.. they don't talk about. Do you wish they were talking about other things?*

**Translations.** Interviewee reply.

**She's saying that you know she has a child and when she's making food for the child she she doesn't feel right you know she wishes that the child wouldn't use the same spoon that she's using or when she's making a drink that she..the child.. wouldn't touch the glass that she's been using. Or maybe is it safe for the child to live with her? Is it a safe environment..she is HIV positive...is it safe for the child to live with her? So she's asking that.**

*Right. Okay. Well, it is. But, I'm not here to give advice right now. But, that's good that we can include that in the future. And she can find out all of those answers at the clinic, definitely, just so she knows.*

**Translations.**

*But it's good to know because those are things that should be included. Yolanda told us that some of the words were really difficult to understand. Have you been able to understand them or do you find that they're too...deep?*

**Translations.** Interviewee reply.

**She says that the ones that she's been receiving, they are not that difficult to her. Because she understands them.**

*And did any of the SMSs make you wonder other questions..have they brought up things in your life that you didn't think about before and now you have more questions?*

**Translations.** Interviewee reply.

**They are okay.**

*So do they ask more..they don't bring up more questions for her?*

**No**

*Okay. In SA, there are obviously a lot of health issues that we have to deal with..do you think people are well educated on all of the health issues? And do you think there are enough resources for people to find out information? Or do you think people need more information and resources?*

**Translations.** Interviewee reply.

**She said the resources are not fine. Because if she goes to the clinic and wants them to explain something to her she doesn't feel that they have answered enough for her. When she goes out there's still a lot that she still wants to know. She doesn't feel that it's enough.**

*And do you speak to..I know you said you spoke to some friends about your SMSs but do you speak to your family about theses SMSs as well?*

Yes (nods head)

*Do share a phone or do you have your own phone.*

**Translations.** Interviewee reply.

**She has her own phone.**

*Okay. And, how would you feel if someone saw the SMSs on your phone..are you fine with that? Do you want to keep them private?*

**Translations.** Interviewee reply.

**She says that she doesn't mind because maybe there's something that the person will learn from the SMSs so she doesn't mind if someone sees them.**

*That's good. And, are you signed up for any other cell phone programmes, SMS programmes? Or is this the only SMS programme?*

**Translations.** Interviewee reply.

**This is it.**

*And the SMSs come every day at the same time..do you like that or do you wish that they would come at different times?*

**Translations.** Interviewee reply.

**There are okay at that time.**

*Okay. What are you doing at 5 o'clock? If you don't mind me asking..*

**Translations.** Interviewee reply.

**She's at work..she's knocking off at 5.**

*Okay. And it doesn't disturb your life..them coming at 5?*

No..

*That's good. These SMSs will come for 3 months and then the programme is over. Do you like that 3 months? Would you prefer that is' longer? Shorter? 6 months be better?*

**Translations.** Interviewee reply.

**No they can stop in that 3 months..if they're going to start again.**

*I don't know if they'll start again..as of now..because that's why we're doing these interviews to see how it can be changed for the future. But you would sign up again if they continued later?*  
yes

*So that's kind of the end. I'm wondering, I really appreciate you coming here to talk to me and I'm wondering, why were you compelled to do this interview? What made you want to come here?*

**Translations.** Interviewee reply.

**She said that she received an SMS saying that they are people there is going to be interviews seeing that people how are they receiving these SMS and then she says that she wants to make sure that she wasn't playing around..she was serious about these SMSs..this programme.**

*That's really good. Well, thank you very much. I really appreciate it. That is the end of our interview.*

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