Factors associated with refusal to participate in HIV surveillance in rural KwaZulu Natal, South Africa

by

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Assignment presented in fulfilment of the requirements for the degree of MPhil (HIV/AIDS Management) in the Faculty of Economic and Management Sciences at Stellenbosch University

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April 2014

DECLARATION

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February 2014

DEDICATION

My dedication on the success of this thesis is to God Jehovah for His gift of loving to read, to write and persevere. To my academic friends: Xolile Kineri, Dumo Mkhwanazi and Makandwe Nyirenda, for encouraging me throughout my studies.

To my late mother for ensuring I achieve my utmost best through education from infancy until completion of my Matric.

To the participants who took part in this study and to all the individuals infected and affected since the emergence of HIV and AIDS pandemic.

Lastly, my gratitude goes to my family, Fezeka Msane, Andile Msane, Milo Mfeka and Zandile Mdletshe.

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ACKNOWLEDGEMENT

I am indebted to those who made my studies towards MPhil a huge success by giving me their untiring love and support until the end. I am humbled and my special gratitude goes to my supervisor, Professor Elza Thomson of Stellenbosch University. To the lectures of Stellenbosch University especially, Professor Jan du Toit, Mr Burt Davis, Professor Johan Augustyn and many others, your good work on HIV and AIDS is great.

To Professor Marie-Louise Newell for the guidance and support from the first day I approached her about the study. Her support even when she had left the Africa Centre is much appreciated. I also wish to thank her for the financial support towards my studies. I thank her for the guidance, support, mentoring and trust shown towards my research work

I am humbled by the support from Colin Newell who assisted with the layout of the questionnaires, his encouragement and laughter when things got so difficult with the research documents.

I wish to express my sincere gratitude to Dr Kobus Herbst of the Africa Centre for spending his time scrutinising each and every word in my research documents and for the provision of data set. His analytical skills assisted tremendously on how to write scientifically. His patience is much appreciated as I sometimes, got very pushy for his assistance towards my research needs.

Special thanks Mr Gareta Dickman, Mrs Natsayi Chimbindi, Mr Makandwe Nyirenda and Dr James Ndirangu for all their support, guidance and mentoring throughout my research work.

My humble gratitude also goes to the former Head of External Relations, Mr Mbongiseni Buthelezi who undoubtedly have faith in my ability when I was still busy with my Postgraduate diploma until I told him I wanted to enrol for MPhil and he undoubtedly encouraged me to register.

Xolile Kineri is much appreciated for data capturing the completed forms from the field and Astrid Treffrey Goatley is appreciated for her guidance on the refusal questionnaire.

Bronwyne Coetzee's support towards this thesis is also acknowledged. Her time spent browsing and emailing the useful links on how to write a good thesis is very commendable. This thesis would not have been accurately completed timeously without her professional support.

I also wish to express my sincere gratitude to the Africa Centre Community Advisory Board members for their endorsement that this study is good as it will help us identify factors that constitute to refusals within the DSA.

I wish to thank Pat Schmidt, Rhana Naicker, Suzette Gobbler, Jabulani Nkosi, Bukhosibemvelo Dludla, Thecla Mkhize, Bab Nkosi, Delisile Sibiya, GIS section, Mr Sabelo Ntuli of the Africa Centre for the entire roles played towards the success of my studies, I am very much humbled.

To my family especially Fezeka, Andile and ZaManguni (Milo), you were such an encouragement when I felt I could not continue due to tiredness. I love you lots. To Milo's dedicated super nanny, Zandile Ngomane, I wish you well and thank you for being always there for her when I was spending most time studying and without any sad face you told me to study as you have skills on how to calm her down.

To my colleagues, especially Ntombi Mncwango, Miliswa Magongo Mangeni and Dumisani Mlondo, you are all appreciated for always understanding during the whole year of 2013.

Siyabonga “Nkosi’ Nxumalo is highly appreciated for his humbleness, promptness and positive attitude in assisting with data analysis. I was humbled by his undivided attention towards the success of this research.

ABSTRACT

Africa Centre for health and population studies (AC) their focal point on research is HIV surveillance, demography, and other contagious diseases such as Tuberculosis and sexually transmitted diseases. The Africa Centre collects demographic data from a population of 90 000 residing in bounded structure estimated at 12.000 in the Demographic Surveillance Area (DSA).

In the HIV surveillance, individuals are anonymously tested for HIV at their homes by fieldworkers on annual basis through a finger prick and drop of blood is placed on filter paper. When participants are asked to give blood samples, some refuse to participate in the HIV surveillance. Knowing that is voluntary, participants are given right to refuse and records are kept in Africa Centre Demographic information System (ACDIS) so as to keep track of the number of individuals who have refused to participate in the surveillance.

The objective of this study was to identify factors that make men and women of the Mpukunyoni community refuse to participate in the HIV and Health surveillance in order to devise strategies that could increase the HIV uptake so that the community members could be informed about the HIV prevalence to enable them to take special precautions about their wellbeing.

Thirty (30) participants who had refused more than once between 2007 and 2012 were randomly selected from the ACDIS data base. Interviews were carried out at their homes and refusal questionnaire was used for data collection. For qualitative approach, thematic analysis was used to analyse the contextual meaning of the text while frequencies and percentages were used for participant's demographic information.

Almost 67% of participants did not show any understanding of the Africa Centre activities while 27% refused because they use their doctors for HIV testing. The study found 46% of participants refused to participate because after having been tested by Africa Centre Fieldworkers, they did not get their results

Seventeen percent of the participants had never been asked to provide finger prick sample by AC field workers but they were found in the refusal list. Fear of the breach of confidentiality by Fieldworkers was reported by 18% of the participants. Another dimension which was found was 38% of participants reported that they have been asked and agreed to give their blood sample but they are recorded as refusals.

Community education and awareness about health and HIV surveillance is essential to inform participants that even if they had signed informed consent for HIV testing, they would not get their HIV results and those results cannot be linked back to them as well as that the test is for measuring HIV prevalence estimates in the community. Moreover, Field workers need to be trained on the importance of accurate information when collecting data. Reviewing other strategies like incentives, need to be explored in order to increase uptake in the HIV surveillance.

OPSOMMING

Die Africa Centre for Health and Population Studies (AC) se navorsingsfokus is op MIV-waarneming, demografie en ander aansteeklike siektes soos Tuberkulose en seksueel-oordraagbare siektes. Die Africa Centre versamel demografiese data van ‘n bevolking van 90 000. Hierdie bevolking bly in ongeveer 12 000 huishoudings in die Demografiese Waarnemings Area (DSA).

As deel van die MIV-waarnemingsprojek, toets die veldwerkers jaarliks individue anoniem vir MIV. Hierdie toets word tuis gedoen deur ‘n vingerprik en ‘n druppel bloed van die deelnemer word op ‘n filtreerpapier geplaas. Hierdie opname is vrywillig en sommige deelnemers weier deelname aan die opname. Die Africa Centre hou ‘n rekord in die Africa Centre Demographic Information system (ACDIS) van deelnemers wat deelname geweier het.

Die doel van die studie was die identifisering van faktore wat mans en vrouens van die Mpukunyoni gemeenskap deelname laat weier aan die MIV- en gesondheidswaarnemingsprojek, om sodoende ‘n strategie te beding wat kan help om die toestemming tot MIV-toetsing te verhoog. Nog ‘n rede is sodat die gemeenskapslede beter ingelig kan wees oor die voorkoms van MIV en die insidensie daarvan, sodat hulle beter voorsorg kan tref om na hulle eie gesondheid om te sien.

Dertig deelnemers wat alreeds meer as een keer deelname geweier het tussen 2007 en 2012, is gekies van die ACDIS databasis. Onderhoude is gedoen deur die vrae op die weieringsvraelys aan die deelnemers te stel. Vir die kwalitatiewe analise is

tematiese analise gebruik om die kontekstuele bedoeling van die teks en die frekwensies en persentasies is gebruik vir die deelnemer se demografiese informasie.

Bykans 67% van die deelnemers verstaan nie die Africa Centre se aktiwiteite nie, terwyl 27% weier omdat hulle hul eie dokters gebruik vir MIV-toetsing. Daar is verder gevind dat 46% van deelnemers deelname weier aan die MV-waarnemingsprojek omdat hulle nie hulle toetsuitslae kry nadat hulle deur Africa Centre veldwerkers getoets is tydens tuisbesoeke nie, selfs nadat hulle meegedeel is dat die toetse anoniem is. 17% van die deelnemers was nog nooit deur Africa Centre veldwerkers gevra om ‘n vingerprik te doen om ‘n monster te gee nie, alhoewel hulle name op die lys verskyn van deelnemers wat geweier het. Vrees dat veldwerkers nie konfidensialiteit sal handhaaf nie is deur 18% van die deelnemers ge-opper. Die resultate toon dat 38% ingestem het om te toets, maar hulle is gelys as deelnemers wat geweier het.

Gemeenskapsopvoedig en bewusmaking oor gesondheid en MIV-waarneming is belangrik om deelnemers in te lig dat selfs indien hulle ‘n toestemmingsvorm geteken het vir MIV-toetsinge, hulle nie hulle toetsuitslae sal ontvang nie en dat die uitslae nie aan hulle gekoppel kan word nie. Dit is verder belangrik dat hulle verstaan dat MIV-toetsing gebruik word om MIV voorkoms in die gemeenskap te bepaal. Veldwerkers moet goed opgelei word in die belangrikheid daarvan om korrekte inligting te versamel. Die hersiening van ander strategieë soos aansporings moet ondersoek word om deelname aan die MIV-waarnemingsprojek te verhoog.

LIST OF ACRONYMS

AC	Africa Centre for Health and Population Studies
ACDIS	Africa Centre Demographic Information System
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral drugs
CAB	Community Advisory Board
CEU	Community Engagement Unit
DSA	Demographic Surveillance Area
DSS	Demographic Surveillance System
GUN	Gunjaneni Reserve
HIV	Human Immunodeficiency Virus
KMI	KwaMsane Reserve
KMT	KwaMsane township
NDV	INdlovu Village
RFS	Refusal
UNAIDS	Joint United Nations Programme on HIV and AIDS
USAID	U.S Agency for International Development

Key words: Refusal to participate, Finger Pricking, Demographic Surveillance Area, South Africa

CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

Joint United Nations Programme on HIV/AIDS (UNAIDS) global report showed 34 million people were living with HIV by the end of 2011 worldwide (UNAIDS, 2012). It further states HIV prevalence is 25% higher in the sub Saharan Africa in comparison to Asia. In regions such as Middle East and North Africa, the pandemic has increased by 35% while the HIV incidence also increased in Eastern Europe and Central Asia even though it was stable in the late 2000s (UNAIDS, 2012).

The Sub Saharan region still has a higher rate for people living with HIV when compared with other regions as it is estimated 23.5 million adults and children are living with HIV. AIDS related deaths amongst adults and children between 2005 and 2011 were reported to be 1.2 million while 1.8 million new infection occurred amongst adults and children between 2001 and 2011 (UNAIDS, 2012).

The Africa Centre for Health and Population Studies has conducted demographic research in order to monitor changes on the population estimated at 90.000 residing at approximately 12.000 bounded structures (BS). Demographic Surveillance System (DSS) was established in the year 2000 after mapping of the Demographic Surveillance Area (DSA) in 1998. The Africa Centre receives its funding from Wellcome Trust based in the UK.

Due to the rapid spread of HIV epidemic, the population-based HIV testing was established in annual rounds in the year 2003. Eligible individuals were those aged 15-49 and were visited by the Africa Centre Fieldworkers at their homes.

The problem in this area is the number of people who refuse to participate in the HIV surveillance is increasing each year. Reports states between 2009 and 2012, refusals have been high (44%: personal communication, Dr A Malaza).

If more and more participants can refuse to participate in the HIV surveillance, it will be difficult to monitor the HIV prevalence, morbidity and mortality due to HIV and AIDS pandemic. This could also mean an increase in infection because people would not know what their status is with the human immunodeficiency virus. Nyirenda M, 2005 reported the number of people living with HIV is unknown because not all consent to participate in the HIV surveillance at the Africa Centre (Previous assignment for 17388554: 2012).

1.2 THE RESEARCH QUESTION

The individual HIV surveillance study visits participants aged between 15 and 49 years and ask them to give a small blood sample through a finger prick for anonymous HIV testing. Some of them refuse to give their blood to the Africa Centre Field workers. There was no reason why the men and women in the Mpukunyoni community refuse to participate in this study. (Boerme et al, 2003). Rice (2007) and Wambura cites HIV surveys and surveillances are the main data source for identifying the HIV prevalence and incidence worldwide. They further suggest surveillances can assist in indicating the HIV and AIDS treatment and influencing the prevention policies (Boerme *et al* 2003 and Rice 2007).

The research question of the study was: What are the determining factors that make men and women in this community refuse to participate in the HIV and Health surveillance?

1.3 THE SIGNIFICANCE OF THE STUDY

The Africa Centre has conducted its research on individual basis from 2003. Since the study began, there has been an alarming rate of non-participation by individuals of different ages. This study would have a great influence on the Africa Centre surveillance because once the reasons can be identified that make participants refuse; the Africa Centre researchers will conduct their research in a manner that could increase the uptake.

If participants can together with researchers understand the importance of surveillances, they could learn from the number of the infected individuals in this area through the Africa Centre newsletter and road shows. Participants therefore could then get encouragement to visit clinics to get tested and be monitored for opportunistic diseases such tuberculosis and would receive treatment immediately once they are diagnosed with the disease. They could also access antiretroviral treatment as soon as they become eligible while they are still healthy and are able to visit clinics on their own hence reducing burden of being taken to clinics by their family members when they become bedridden due to AIDS related illnesses.. The Community Engagement Unit will also where the burden of visiting homes to do refusal verifications will utilise time to raise more awareness on HIV preventative measures.

1.4 AIMS AND OBJECTIVES

The aim of this study is to identify factors that decrease the HIV uptake amongst the participants in the HIV surveillance longitudinal survey in order to devise strategies that could increase the HIV uptake in this community so that participants can be

informed about the HIV prevalence in this community to enable them to take special precautions regarding their health.

The objectives were:

- To identify the number of men and women in the Mpukunyoni community who refused participation
- To identify personal reasons for refusing participation in the health and HIV surveillance in this community
- To establish participants' perception about the Africa Centre research and its employees, especially Fieldworkers regarding HIV and Health Surveillance
- To observe the characteristics of the participants that refuse HIV and Health surveillance, for an example, their age, gender, educational level, their geographical settings, employment status, preferred HIV testing location and whether they have access to medical aids or not
- To improve the trust and relationship between the researched participants and Fieldworkers

1.5 RESEARCH METHODOLOGY

An interest was shown in understanding reasons that made men and women in the Mpukunyoni community refused participation in the HIV surveillance. Qualitative approach was used in this study. This allowed the participants to express their views and concerns about the HIV surveillance study. This approach gave the opportunity to understand the attitudes of the participants about the Africa Centre and its research.

1.6 LIMITATION OF THE STUDY

Since HIV is a sensitive issue, some participants felt uncomfortable to express their views on why they refused participation in the HIV surveillance. Another limitation was the sample size (30) was too small to generalize for the whole population, but this study helped to understand some of the phenomenon on issues of refusal to participate in the HIV surveillance. The third limitation of this study was it excluded participants below 20 years old that have refused and it will thus not be possible to establish why they refused participation. These participants were excluded because the study would have fallen in a high risk category where parental consent would be needed because; wanted to minimize the duration of the study according to the academic year.

1.7 CHAPTER OUTLINE

Chapter one covers the introduction, the objectives of the study and the research questions. It also presents the justification of the study and definitions of terms used in this study.

Chapter two gives the investigated literature review on the factors associated with refusal to participate in the HIV surveillances worldwide, global overview, ethical issues, the effectiveness of HIV surveillances, HIV prevalence in KwaZulu Natal as well as trends of HIV participation in the DSA are topics which were explored in detail.

Chapter three give details on methods that were used during this study. This includes study setting, study sample, data collection, and data analysis as well as study design. Chapter four present findings on the study where we look at issues of

HIV understanding, frequencies and percentages of number of participants 'characteristics and their views and concerns about Africa Centre and lastly, chapter five covers the discussion as well as recommendations about what needs to be done in order to increase the uptake in the HIV surveillance.

1.8 CONCLUSION

Chapter one gave the background of the study and the objectives as well as research question. This chapter also gave an insight on the significance of the study and research methodologies. The next chapter is going to look at the literature review in relation to refusal to participate in the HIV surveillances worldwide.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

Participating in health and HIV surveillance study is voluntarily. Since the establishment of this study at the Africa Centre, the rate of refusing to participate has been changing for the worse over the years. This has a negative impact since it will not be able to know whether the HIV incidence and prevalence is increasing or decreasing in this community. The following sections will look at what has been happening in other countries with regard to increasing rates of refusals. This chapter is also going to give details on HIV and AIDS pandemic globally.

2.2 THE GLOBAL OVERVIEW ON HIV AND AIDS

UNAIDS global reports (2012) states 34.0 million people are living with HIV at the end of 2011. It further states 0.8 adults between the age of 15 and 49 are already infected with the virus and the pandemic varies per regions and countries (UNAIDS 2012). This show all humans are faced with a crucial problem which needs a decisive action in order to reduce the spread of the pandemic globally.

There have been a decline in HIV incidence rates amongst adult between 15 and 49 years in certain countries between 2001 and 2011 (UNAIDS, 2012); in other regions the incidence rates continue to rise. According to UNAIDS report countries such as Indonesia, Georgia, Philippines Bangladesh, Sri Lanka and Republic of Moldova the rate is increasing by more than 25%. Countries in different part of the world namely Belarus, Angola, Benin, Gambia, Nigeria, Uganda, Republic of Tanzania and United States of America the pandemic is relatively stable (UNAIDS, 2012).

When comparing with countries such as Burundi, DRC, Jamaica, Kenya, Malaysia, South Africa, Swaziland and Cameroon the HIV incidence rate decreased 26-49% by 2001-2011(UNAIDS, 2012). Some countries that have more than 50% decrease in high incidence rates are: Bahamas, Botswana, Burkina Faso, Cambodia, Ethiopia, Gabon, Ghana, Haiti, India, Malawi, Namibia Rwanda, Thailand, Zambia and Zimbabwe(UNAIDS, 2012).

The Global report (2012) claims the death rates due to AIDS related diseases is estimated at 1.7 million worldwide in 2011 which is a reduction compared to 2005. This decline was due to the scaling up of ARVs in many countries that were affected by the pandemic (UNAIDS, 2012).

Bärnighausen et al (2012) reports there are an improvement in the quality of life for individuals in KwaZulu Natal, South Africa after they start ARVs. He further on states the likelihood of being employed after an individual has started ARVs increase up to 40%. The global report also states when considering adults and children living with HIV per region, the sub-Saharan is leading because it is estimated that 23.5 million are living with HIV in 2011. Out of 34.0 million of people living with HIV, it means the Sub-Saharan region has the highest rate of infection represented by 34.0 million globally; 23.5 million in Sub-Saharan Africa. With these high rates of HIV infection, UNAIDS claims behaviour change is contributing to the decrease of HIV infection in some countries. Factors required reaching the zero new infections are condom distribution, VCT, male circumcision, focused programmes for sex workers and access to ARVs (UNAIDS, 2012).

Lomborg (2012) reports 80% of HIV transmission occur due to unprotected sex worldwide. Lomborg (2012) believes even though paid sex is one of the important sources in HIV transmission, a high number of HIV transmission is not related to paid sex.

2.3 THE ETHICAL ISSUES REGARDING ANONYMOUS HIV TESTING

There have been many controversies regarding anonymous HIV testing. Literature shows anonymous HIV testing has been conducted in the United States and other countries since 1990 and has shown to be successful (Zulueta, 2000). These theorist further states individuals had their autonomy respected during the surveillance. This study was conducted amongst women attending antenatal care after they have been offered informed consent. Zulueta (2000) further states even though some pregnant woman understood the rationale of anonymous testing, certain of them agreed to give blood samples whilst others refused.

Nicoll et al indicates anonymised HIV testing is useful in monitoring the epidemiology of HIV. Nicoll (1990) further suggests these types of surveys have been accepted by the health professionals and the public's they further conclude anonymous HIV surveillance forms essential part of the national HIV and AIDS surveillance.

National HIV prevalence in many countries is usually estimated by the number of women attending antenatal care. The blood sample is collected from patients for HIV tests which are anonymised and unlinked to the person giving the sample. According to the World Health Organisation, unlinked anonymous HIV testing without the informed consent should be conducted at the clinic because blood could also be used to detect other diseases such as Syphilis (WHO:2012). WHO (2004) released a document addressing ethical dilemmas regarding anonymous HIV testing stating

'communities should be broadly notified that blood collected for one purpose may be anonymously tested for HIV'.

2.4 THE EFFECTIVENESS OF HIV SURVEILLANCES OR SURVEYS

The HIV surveys have proven to be more effective in many ways. The Division of HIV/AIDS Prevention (DHAP) in the Centers for Disease Control Prevention developed the comprehensive programme of HIV surveillance to collect analyses and disseminate data on the infection. The purpose of the programme was to monitor HIV and AIDS in the United States (AIDSInfo, 2008).

The first case of HIV amongst gay men in 1981 was the work of surveillance where a form of rare pneumonia was identified. Since then Columbia and six dependent areas namely, American Samoa, Guam, Northern Island, Puerto Rico Republic of Palau and US Virgin Island took part in the HIV surveillance with unidentified information (AIDSInfo, 2008).

AIDSInfo (2008) further claimed data collected through surveillance assists in understanding the burden of diseases which in turn helps to guide the public health on the number of infections in order to plan and allocate resources according to the HIV surveillance. In addition AIDSInfo continued to state the HIV survey assisted in the United States to monitor the transmission patterns amongst people.

2.5 CAUSES OF REFUSAL TO PARTICIPATE IN THE HIV SURVEILLANCES IN DIFFERENT COUNTRIES

A representative HIV survey was conducted in the UMkhanyakude district, KwaZulu Natal and it was found where refusal to participate in the HIV surveillance was 37%

excluding absentees and non-contacts (Nyirenda, 2005). Information on health and sexual behaviour and blood sample was collected from 2000 women aged 15-49, and men aged 15-54 since 2003. In 2005 59% refused to give blood for HIV testing and the status for refusal was marked as unknown. Refusal to participate has been increasing in the UMpukunyoni community for different reasons.

According to a study to understand patient acceptance in the emergency department conducted in San Francisco, it was reported the proportion of patients who accepted HIV testing varied widely from 24% -91% (Christopoulos, Weiser, Koester, Myers, White, Kaplan and Morin, 2012). Christopoulos *et al* further states accepting or refusal to test depended on how patients perceived their HIV status. Individuals who did not consent to HIV testing were at greater risk of infection. When researchers tested un-identified blood samples in Washington D. C from those refusing HIV testing, infected blood samples were found to be contaminated three times more than those that had accepted these tests (Christopoulos *et al*: 2012). Christopoulos further found reasons for refusing HIV testing where patients reported feeling sick and some hold perceptions were at low risk of this infection (Christopoulos *et al*: 2012).

Evidence according to Matovu & Makumbi (2007) is even high though ARVs are accessible to those eligible in the Sub-Saharan countries where fewer than one in 10 people know their HIV status. They further state reasons for people not consenting to voluntary counselling and testing are stigma, fear of knowing their HIV positive status, fear of confidentiality about HIV positive results cannot be kept confidential and distances to clinics was a problem.

Rennies & Eaton (2009) Barnighausen et al. (2011) states infected individuals were more likely to refuse HIV testing as they fear to confirm positive results and confidentiality would not be maintained.

It was reported 800.000 children had contracted HI virus1 from their mothers in 2001 and 87% of the infections were in the sub-Saharan countries due to the unknown serostatus of women (UNAIDS 2007). Pool et al (2009) in Uganda claims although pregnant women were willing to test for HIV, they were anxious about confidentiality of their positive status and they feared maternity staff would ill-treat them once they determine where they are in their lives.

According to Coulibaly et al. (2008) in the mother to child transmission in Abidjan, reports pregnant women who were asked to participate in study, agreed but never came back for their results. Some who refused participation reported they suspected being already infected and confirming their status with the test was going to accelerate the progression of the disease due to fear. Some felt pregnancy was not the appropriate time to undergo an HIV test.

Evidence by Cartoux *et al* (2000) found similar findings in Abidjan with low rates (7.6%) and Burkina Faso (22%) women refused participation saying they needed permission from their husbands or partners. Cartoux (2003) also found higher educational level was one of the predictors of refusal to test in Bobo-Dioulasso where ignorance of the main mode (sex) of HIV transmission in Abidjan and main form of prevention (condom use) was associated with refusal to test.

In a study conducted in Malawi it was found individuals refused HIV test because of negative social consequences in a form of family disruptions, stigma and discrimination against women (Keogh et al, 2006, Maman et al, 2000).

In contrast Cartoux (2000) in an international survey in 1997, PMTCT of HIV in developing countries found despite many obstacles; VCT was feasible and acceptable for pregnant women. Acceptance was between 53% and 99% in sub-Saharan countries. Similarly in Lusaka, Zambia, Wilkinson (2003) was of the view rate of accepting HIV testing ranged between 72% and 90% amongst antenatal women. In contrast, Fylkensness, Ndlhovu, Kasumba and Mubanga (2009) found in rural and urban areas of Zambia, people were unwilling to undergo voluntary counselling and testing because they felt they were not at risk of infection.

Temmerman (2003) found women who were counselled by the investigators to tell their partners about their HIV status in Kenya, 11 were chased away from their homes or replaced by other women; seven were beaten up while one committed suicide. In Kigali, Rwanda getting one's results was optional and only 35% came back for their results in a study that looked at whether participants could return for post-test counselling if it was made optional (Ladner, Leroy, Msellati et al. 1993).

In South Africa, Bärnighausen, Tanser, Gqwede, Mbizana, Herbst and Newell (2008) in a study measuring HIV incidence amongst community members, found consent rates of repeated HIV testing was low. In another randomised study conducted in Malawi, reasons for refusals to test for HIV was because they already knew their status. Some men and women reported they were not at risk of HIV infection while others reported fear of needles and anaemia (Kranzer et al. 2005-06).

A study conducted near the small town of Mtubatuba, Giordano et al (2007) found 61% of individuals who repeatedly refused to participate in the HIV surveillance responded with dislike for blood being taken while 36% indicated they already knew their HIV test results. Giordano et al (2007) further states males were more likely to

refuse than females. Education and wealth were predictors of repeated refusal to participate in the HIV surveillance (Giordano et al, 2007).

2.6 THE HIV PREVALENCE IN SOUTH AFRICA ESPECIALLY IN KWAZULU NATAL

Statistics South Africa reports in a study based on a sample of 36 000 women attending antenatal clinics in all provinces, 29; 5% of pregnant women aged 15-49 were living with HIV in 2011(South Africa HIV &AIDS Statistics, 2008). This report further states even though the pandemic was spreading fast in 1998, the increase became stable in 2006. In South Africa HIV prevalence is estimated at 17.8% while its incidence is at 1.49% amongst people aged between 15 and 49 (AIDSInfo, 2009). The UNAIDS strategy aims to empower young people to make informed decisions about their behaviour and health aiming to reduce new HIV infections (UNAIDS, 2010). This could be best achieved by increasing intervention programmes including condom distribution, PMTCT and male circumcision in response to HIV and AIDS pandemic.

In KwaZulu Natal the HIV prevalence is higher when compared with other provinces. The incidence in KwaZulu Natal increased from 33.5% in 2001 to 37.4% in 2011 (South Africa HIV &AIDS Statistics, 2008). Results in this survey provide evidence the HIV prevalence is higher amongst participants between 25 and 29 years old with the peak at 30-34 years old. The results of the survey further states KwaZulu Natal, Mpumalanga and Free States had high HIV prevalence in 2008 (South Africa HIV &AIDS Statistics, 2008).

In another study conducted in KwaZulu Natal, Nel et al (2007 and 2012) found the HIV incidence was high and it was also reported amongst sexually active women between 18 and 35 years; HIV prevalence and incidence continued to be high in KwaZulu Natal. In a similar study Reynolds et al (2010) also found 24.1% of the total population surveyed in KwaZulu Natal were HIV positive.

2.7 THE TRENDS OF HIV PARTICIPATION IN HIV WITHIN THE DSA

Table 2.1 shows the nature in which the number of the eligible members in the early years when HIV surveillance was first established in round one to round three. There is an indication where out of 19 887 only 11 551 individuals consented to participate. It raised an alarm in round three whereby, out of 21 387 individuals contacted only 8.136 consented to participate leaving 13 251 participants as refusals.

Table 2.1

CONSENT TO PARTICIPATE

	Eligible	Contacted	Consented
R 1 (2003-2004)	25 901	19 867	11 551
R 2 (2005)	22 357	21 936	8 909
R 3 (2006)	23 338	21 387	8 136

Source: Welz et al. 2007

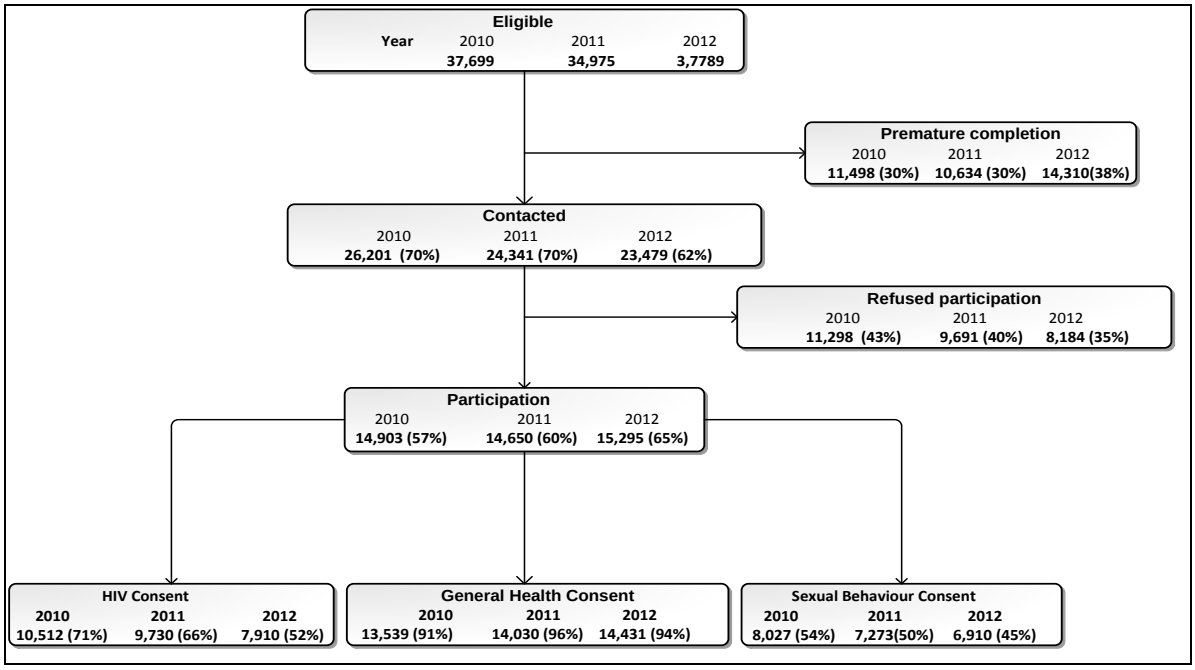
Findings in HIV surveillance show a slight variance in terms of participation in the years 2010, 2011 and 2012. In 2010 and 2011, 70% of individuals were contacted 43% and 40% respectively refused to participate in the HIV surveillance. Even

though the rates of refusal slightly decreased to 35% in 2012, still this is a noticeable level which could reduce the monitoring of the HIV pandemic prevalence in this community.

When viewing the consent rate on HIV test (finger pricking) from 2010 till 2012, the range is 71% to 52% and this is high of individuals who did not give their blood sample for HIV testing which is the core of the surveillance. Figure 2.1 depicts the trend in the HIV surveillance consent rates.

Figure 2.1

HIV SURVEILLANCE CONSENT RATE



The trends of Dried Blood spots in the HIV surveillance, extracted from unpublished report by Dickman M, 2013 March

2.8 CONCLUSION

This chapter presented literature regarding refusal to participate in different countries. Previous research on HIV surveillance has been discussed in detail. Reasons for refusal to participate in HIV surveillance within the Africa Centre has been portrayed by a table and figure showing the numbers per round and year. The subsequent chapter presents the methodology which was used in this research. It covers the research design, study setting, data collection, data analysis, sample and ethical consideration.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 INTRODUCTION

The HIV surveillance team visit participants at their homes and they are asked to participate by providing a blood sample through a finger prick with the intention of establishing whether the spread of HIV is increasing or decreasing. The collected data on participants refusing to participate is kept by the ACDIS data base. The current study, therefore intends to identify factors that make men and women of the Mpukunyoni area refuse to take part in the health and HIV surveillance conducted by the Africa Centre for Health and Population studies. This chapter summarised the methods used during the study process.

3.2 PROBLEM STATEMENT

The Africa Centre for Health and HIV surveillance endeavours to monitor the HIV prevalence and incidence in the Mpukunyoni community; participation in the HIV surveillance is voluntarily. Since the establishment of the survey a number of participants have been refusing and this has been varying over the years (Reynolds et al, 2010). This study is attempting to identify what the factors are making men and women in this community continue to refuse participation in the HIV surveillance.

3.3 STUDY SETTING

The study was conducted within the Demographic Surveillance area (DSA) in the Mpukunyoni area under the UMkhanyakude district. The local municipalities which serve the researched population are the Hlabisa and Mtubatuba. The DSA consist of 39 catchment areas under traditional Headmen under the leadership of Inkosi

Mkhwanazi in the UMkhanyakude district; four catchment areas were chosen for this study. The areas selected are KwaMsane Township and INdlovu village which are the urban areas with high rates of refusals to participate in research and KwaMsane reserve which is peri urban as well as Gunjaneni area which is a deep rural reserve with less educated individuals and few rates of refusals to participate.

3.4 THE STUDY SAMPLE

Data sets of thirty (30) individuals were provided from the list of participants who have repeatedly refused two or more times, to participate in HIV surveillance. Females (n-15) and males (n=15), aged between 20 and above were randomly selected from the list of surveillance between January 2007 and December 2012. Their demographic data was extracted from the refusal list kept in the (ACDIS See appendix for the data sets.)

3.5 STUDY DESIGN

This study was more qualitative in nature but it incorporated the frequencies and percentages of participants' demographic variables in order to explore the characteristics for those having refused to take part in the surveillance. According to Moustaas (1994) in qualitative research the phenomenon is identified where experiences are explored. One interview per individual was carried out at their homes using the questionnaire.

According to Leedy et al (2005) the advantage of using a qualitative research focus on phenomena occurring in natural settings and incorporated the studying them. Leedy et al (2005) further states some researchers hold the idea that their ability to interpret and make sense of what is observed is critical to understand.

This method was chosen because ideally it can reveal the nature of what is being studied and factors that make participants refusing participation in the HIV surveillance (Leedy et al:2005).

3.6 DATA COLLECTION

A questionnaire for this study was designed which contained variables such as gender, age, marital status, occupation and level of education. Close ended question were included which aimed at measuring the participants attitude towards HIV surveillance. The last five themes were to establish the reasons why participants had refused to take part in the HIV surveillance.

Home visits were done between November 2013 and December 2013 and interviews took between 20 and 45 minutes depending on the responses given by the participants. The main challenge was not finding the participants but the visits had to be extended to include evenings and weekends.

3.7 INCLUSION CRITERIA

These participants were only eligible if they were resident members of KwaMsane Township (KMT), Kwa Msane Reserve (KMI), INdlovu Village (NDV) and Gunjaneni (GUN) reserve at the time of refusal even if they have moved from these areas as long as they were still resident's members within the Demographical Surveillance Area (DSA). They were also eligible if they were aged between 20 and above when they refused participation in HIV surveillance. Participants had to be full members of the households within the DSA and who had refused two or more times between January 2007 and December 2012.

3.8 EXCLUSION CRITERIA

Participants younger than 20 years and whose status is Avoid Permanently (AVD) in the ACDIS data base and those who were not resident members of KMT, KMI, NDV and GUN at time of refusal as well as those who have moved out of the DSA even if they have refused while being resident members at KMT, KMI, NDV and GUN, were not eligible for the current study as well as those who were not residents in the DSA in December 2012.

3.9 DATA ANALYSIS

Content analysis was used for this research qualitative, percentage and frequencies were used (Leedy & Ormrod, 2005). Percentages and frequencies were used to summarise gender, age, marital status and occupation in tables (Leedy & Ormrod: 2005).

Furthermore, Leedy et al (2005) describes content analysis as a detailed and systematic examination of contents of a particular body of material for the purpose of identifying patterns, themes or biases. Leedy et al (2005) further states the researcher has to define the characteristics when analysing data. Data was recorded for qualitative analysis then transcribed and broken down into smaller segments for easier interpretation. Themes were read repeatedly to look for the appearances for certain words to be interpreted as per interview questions or themes. Themes considered were:

- As a resident member of this community, what can you say about Africa Centre research conducted in this community?

- Have you ever been asked to provide a finger prick specimen within the HIV surveillance by Africa Centre Fieldworkers?
- Was the study properly explained and did you understand why the study is carried out?
- Were you alone when you were asked to participate in the HIV surveillance?
- What do you think we should know in order to encourage community members to participate in the HIV surveillance?
- Do you have any questions or concerns regarding HIV surveillance conducted by Africa Centre?

3.10 ETHICAL CONSIDERATIONS

The participating individual was given all the information regarding the study and the informed consent was signed by both the participant and the researcher. In a case where the participant could not sign, the guardian had to sign on behalf of the participant. Participants were voluntarily taking part in the study and their participation and information was treated with strict confidentiality.

Ethical approval for the study was sought and obtained from the Stellenbosch University. Reciprocity approval was also obtained from the Biomedical Research Ethics from the University of KwaZulu Natal. The Africa Centre community Advisory Board also granted permission to conduct this research in the Mpukunyoni community.

3.11 CONCLUSION

This chapter provided the details of the study methods, sample, data collection and data analysis. It also included the inclusion and exclusion criteria of participants as well as ethical considerations. The next chapter presents the results of the study.

CHAPTER FOUR

REPORTING OF RESULTS

4.1 INTRODUCTION

This part of the report covers the frequency and percentage findings as well as the qualitative analysis where special conclusions will be drawn to identify the reasons of participation in HIV surveillance. The frequencies and percentage findings presents the demographic components of the participants and the qualitative findings are based on the themes or contextual responses on the views or concerns about the HIV surveillance and the Africa Centre research.

4.2 CHARACTERISTICS OF PARTICIPANTS

Participants consisted of 15 females and 15 males who resided at the four catchment areas namely KMT, KMI, IND and GUN (table 4.1). This component was used for the analysis to measure the number and reasons of refusal to participate in the HIV surveillance. This was going to produce philosophies what type of participants were refusing and for what particular reasons.

Table4.1

GENDER

Gender	Frequency	Percent	Cumulative %.
Female	15	50.00	50.00
Male	15	50.00	100.00
Total	30	100.00	

Table 4.2

BIOGRAPHICAL INFORMATION

Age group	**N**	**%**
20-29	5	17
30-39	9	30
40-49	7	23.3
50-59	5	17
60-69	2	6.6
90-110	2	6.6
Total	30	100
Setting		
Urban	16	53.3
Peri Urban	8	27
Rural	6	20
Total	30	100

This study found participants from urban (53.3) setting contributed the highest percentage while there was a slight difference between peri-urban (27%) and rural (20) areas (table 4.2).

The over–sampling technique was not applied during the random sampling which decreased the number from 30 to 24 as one participant had deceased, one refused to participate and four participants had relocated to unknown locations. Married participants (30%) refused to participate as depicted in table 4.3.

Table 4.3

MARITAL STATUS

Marital status	Frequency	Percent	Cumulative %.
Deceased	1	3.33	3.33
Married	9	30.00	33.33
Never married	14	46.67	80.00
Refused	1	3.33	83.33
Relocated	4	13.33	96.67
Widowed	1	3.33	100.00
Total	30	100.00	

This measurement reflected 30% unemployed participants refused to participate while 27% were in full time employed. Self-employed and part time employees was 3% while no information was obtained from 20% of the participants as they were not found at time of data collection due to relocation (*n=4*), refusal (*n=1*) and deaths(*n=1*) (table 4.3 and figure 4.1).

Figure 4.1

OCCUPATIONS

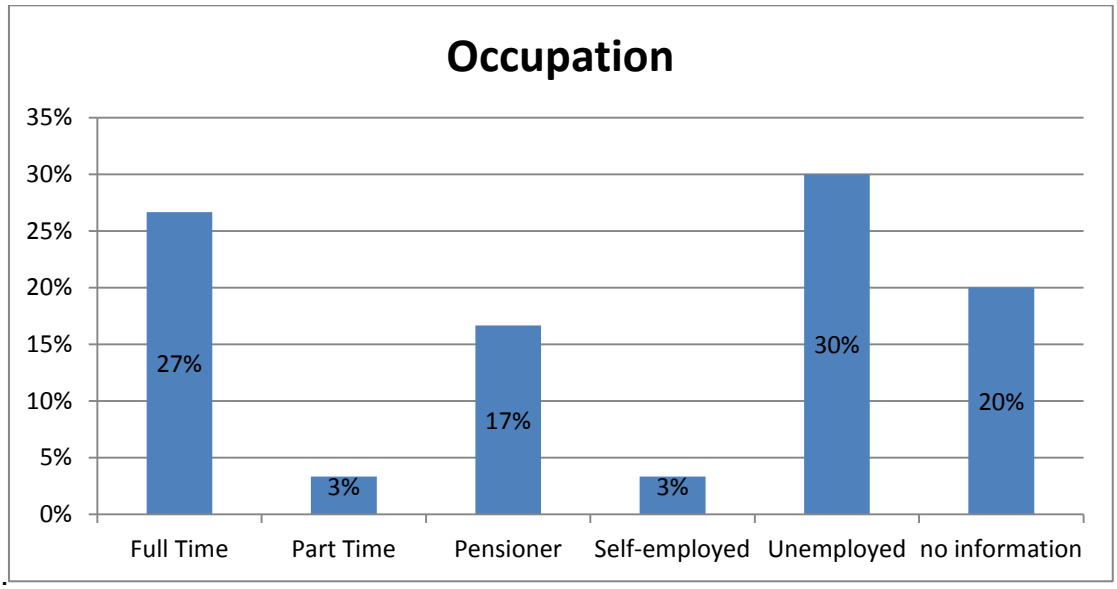


Table 4.4

PARTICIPANTS' PROFILE

Occupation	Frequency	Percent	Cumulative %.
Full Time	8	26.67	26.67
Part Time	1	3.33	30.00
Pensioner	5	16.67	46.67
Self-employed	1	3.33	50.00
Unemployed	9	30.00	80.00
no information	6	20.00	100.00
Total	30	100.00	

Individuals with secondary education forms 33% followed by grade 12 participants (25%) which is a slight difference. Participants with tertiary education contributed to 21% of refusals with a huge difference when compared with those participants with primary (13%) education (table 4.2 and figure 4.5).

Figure 4.2

NUMBER OF ENROLLED PARTICIPANTS BY QUALIFICATION

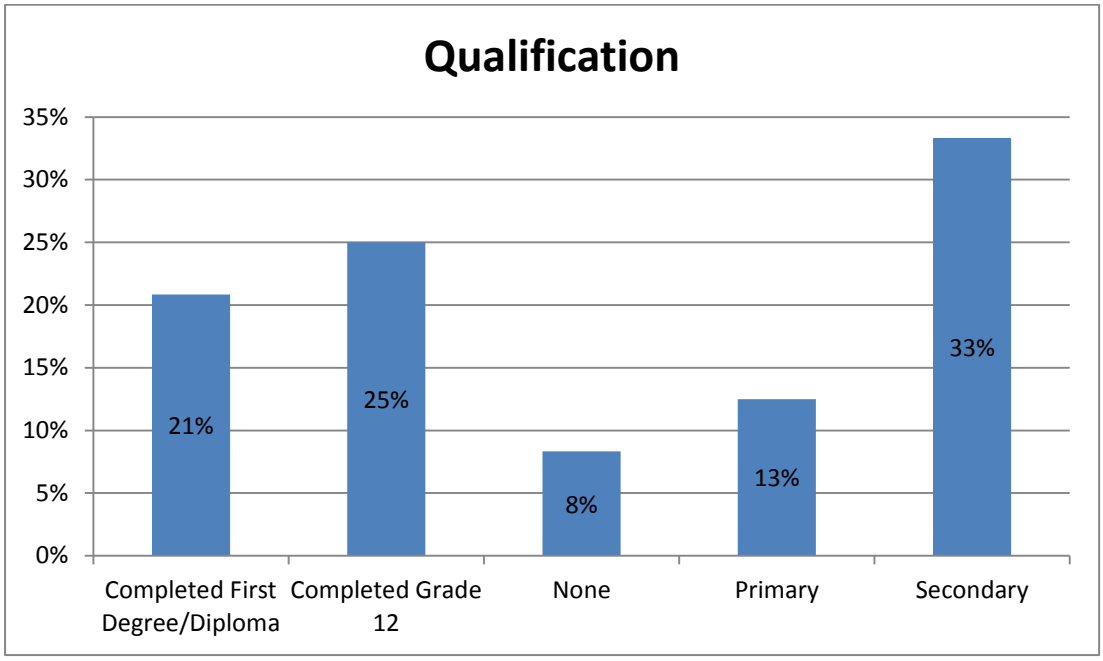


Table 4.5

QUALIFICATIONS

Qualification	Frequency	Percent	Cumulative %.
Completed First Degree/Diploma	5	20.83	20.83
Completed Grade 12	6	25.00	45.83
None	2	8.33	54.17
Primary	3	12.50	66.67
Secondary	8	33.33	100.00
Total	24	100.00	

The individuals were asked whether they would participate in the HIV surveillance by providing a blood sample through finger prick; 83 % responded in the positive. The

study also found of 24 participants at their homes, 17% were never asked to participate in the HIV surveillance. Some of them reported they were either at home or work while some reported to have been always available (figure 4.3).

Figure 4.3

PARTICIPANTS EVER ASKED BY AC FIELDWORKERS TO FINGER PRICK

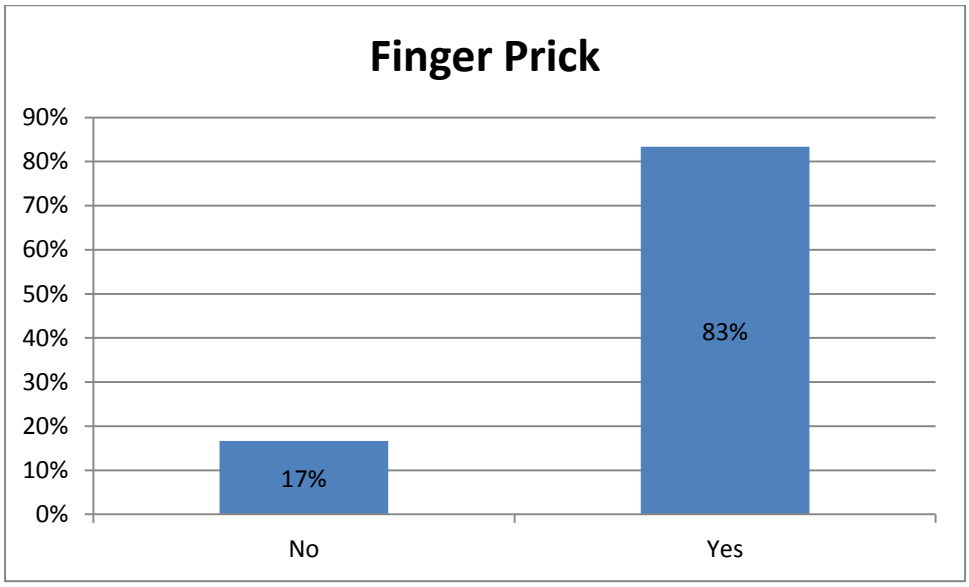
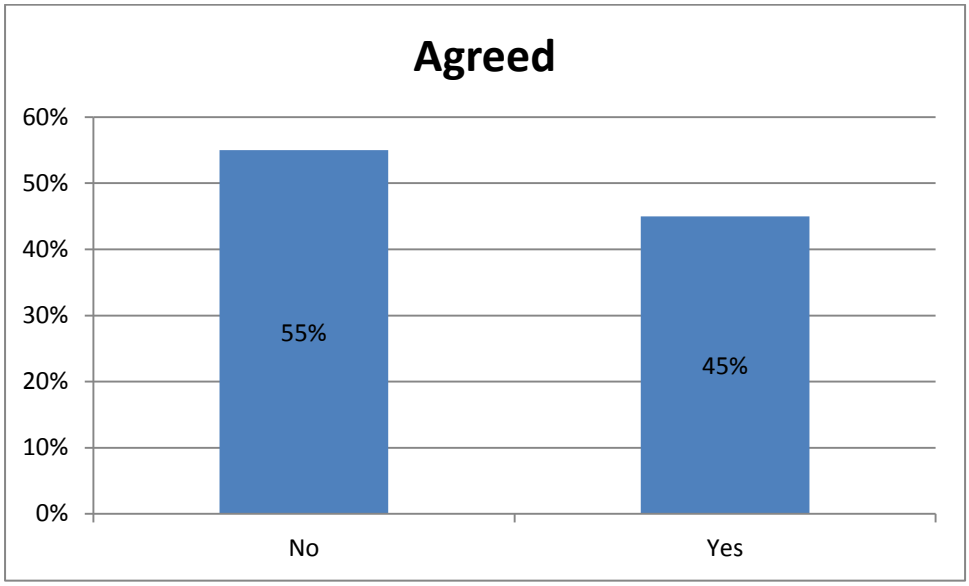


Figure 4.4

PARTICIPANTS AGREEING/ REFUSED TO FINGER PRICK



Participants who were ever asked to take part by fieldworkers were represented by 45% while 55 % refused to be available. A portion of those that had agreed to participate were in the refusal list for the current study because at some stage they did decline more than twice between 2007 and 2012 (figure 4.4 and table 4.6).

Table 4.6

ENROLLED PARTICIPANTS THAT AGREED/REFUSED

Agreed	Frequency	Percent	Cumulative %.
No	11	55.00	55.00
Yes	9	45.00	100.00
Total	20	100.00	

4.3 QUALITATIVE RESULTS

In order to get insight on factors associated with refusal to participate in the HIV surveillance it was deemed necessary to identify a number of factors that were anticipated as measures contributing to the low uptake in the HIV surveillance.

4.3.1 KNOWLEDGE AND VIEWS ABOUT AFRICA CENTRE

Participants were asked to give information on what they know about the Africa Centre and also to share their views on any issue or perceptions regarding the HIV surveillance. A number of themes were then identified from their responses but the most important themes identified were; issues of HIV tests and ARVs; questioning of Africa Centre about the assets; HIV results; and knowledge that AC is a research institution.

4.3.2 ISSUES OF HIV TESTING AND ARVS

The response from participant above shows he had an understanding of what the Africa Centre does whenever they are visiting the homesteads in the DSA:

*The Africa Centre checks how many we are in this community. How healthy we are and they also check blood for HIV infection. I am always giving my blood sample as I saw a need for that because they care for us (*63 year old retired police).

This participant had never been asked by the Africa Centre Fieldworkers to participate in the HIV surveillance. She was only repeating what she had heard from different community members since she is always at work outside the DSA. Myths and conception were corrected in order to avoid false rumours spreading especially because she was from the Ward with high rate of refusals:

'I know that Africa Centre test and find that all people have got AIDS but if you go and check elsewhere you do not have it' (32 year old female).

Eish, I do not see this thing of Africa Centre for always chasing us for our blood as if they are mosquitoes, I don't want it really (25 year old, part time male).

Two participants reported they had refused because they were tested before and felt pains when blood specimen was taken:

I got tested before, why do I have to do it again; this thing of being pricked is very painful (39 year old male).

4.3.3 QUESTIONING ON THE ASSETS

The knowledge portrayed by the community varied greatly because while some participants demonstrated knowledge about Africa Centre and its activities, some were ignorant. The participant's response demonstrated comprehensive knowledge about the Africa Centre because she gave information on demographic research as well as HIV surveillance:

What I know is that Africa Centre asks about membership and new members in our homes. They ask us about our assets like electricity, cars etcetera. They sometimes ask for blood samples to check the level of HIV infection in this community (grade 11, 25 year old female).

4.3.4 UNDERSTANDING THAT AC IS A RESEARCH INSTITUTION

According to some participants the Africa Centre is expected to provide service delivery in order for them to participate in the HIV surveillance. One participant

reported she knew nothing about the Africa Centre except it intends to get blood samples and then give positive results to all those who has participated in the HIV surveillance. The question asked was 'As a resident member of this community what can you say about Africa Centre research conducted in this community? The response given was:

Actually, we do not see help from Africa Centre, we are poor but you keep coming and ask questions. We do not have electricity, any water and toilets, we go to the bush and we do not have proper houses (90 year old female).

Mhhnhh! I know nothing maybe those who participate know something. But Africa Centre staff is good, they do not embarrass and they do not force, they just do what they have come to do (42 year old female).

When looking at the quotes it shows these participants had a negative attitude towards the Africa Centre and they are knowledgeable about the activities performed by the Africa Centre.

The responses from most participants indicate the community members still lack an understanding of Africa research. Some participants, even though they gave precise answers, there are still those who need to be educated on the importance of research and its benefits.

Knowledge about Africa Centre and research conducted; there was a need to understand what attitudes participants might have towards the HIV surveillance study:

There is nothing that I can think of, I am irritated by sitting like this responding to questions while I have got no time, and that I do not know how this research help us (46 year old female teacher).

You see, I do not understand this thing; you always come and go gathering our information but when do you come back and tell the community what you have found. And why don't you make appointment or else come to us on weekends than to always checking on us and when we come home we are told you have been looking for us (55 year old male teacher).

4.4 HIV TESTS RESULTS

Interviews also revealed some participants refused participation because they no longer receive their results:

Because we do not get the results, I have been tested many a times from mobile clinics, at the shop and from clinics but I do not get my results (54 year old male).

Hha! Sisi, it is scary, you cannot just test, what if you are HIV positive? What will happen after that? I will not be able to get 'it from her if we know we are sick' (27 year old male).

This participant admitted of never participating due to being afraid he could be HIV positive; he will not be able to have sex from his partner. During the interview he also reported being young he prefers unprotected sex as he still wanted to produce children.

There were those who are concerned the Africa Centre had been given them their results before but since 2008 things changed. Even though explanation was given to

them during the home visits, they still complained they have a right to know their HIV statuses (46%).

4.5 ATTITUDES TO HIV SURVEILLANCE

Some participants indicated they acknowledged the Africa Centre conducted the HIV surveillance. They applauded since the clinics are always full with long queues, home visits and home testing was useful to the community.

In contrast to anonymous testing which is what the HIV surveillance employ some participants were totally against anonymous testing. They claimed they would agree to participate in the HIV surveillance if they were going to be given their results.

There can be a comprehension of the different attitudes from the study participants when looking at three categories. Those where participants who were asked to provide a finger prick specimen by Africa Centre Fieldworkers but refused to participate, those who were asked to participate and agreed to participate and those that claimed they were never asked to provide a finger prick specimen at all.

4.5.1 PARTICIPANTS WHO WERE ASKED TO PROVIDE A FINGER PRICK SPECIMEN BUT REFUSED TO PARTICIPATE

These participants showed different attitudes and gave various reasons why they had refused to participate in the HIV surveillance by providing a finger prick specimen:

Because I go to my doctor and I had recently been tested (54 year old female nurse).

Hha, if a person wants to know like me, he or she just goes to the doctor not to be visited at home (55 year old male teacher).

These responses were given by participants who are well educated and they were resident members of the KwaMsane Township. KwaMsane Township is a well-developed area with services including tarred roads, electricity, tab water in the house and it is 12 kilometres from a small town called Mtubatuba. In order to measure their attitude to HIV surveillance, it was important to also note their knowledge about the Africa Centre research activities.

A 55 year old male reported the Africa Centre only collects data from the community and no feedback is given of the results. This was considered a problem because the community had been engaged on many occasion by the Africa Centre with the road shows, community meetings, health bashes, focus groups discussions, health music competitions and many other related engagement activities; those attending is always low.

4.5.2 PARTICIPANTS WHO WERE ASKED AND AGREED TO PARTICIPATE

The interviews revealed some participants (33.3%) were not routinely participating in the HIV surveillance. Participants were eligible if they had refused agreeing more than twice in the previous rounds, this category provide evidence of agreeing and refusing participation at certain rounds:

*I once did this thing hoping I would get my results back but it never did. I no longer want to finger prick. The person who tested me lied saying he will bring back my results (*34 year old male).

The best measurement against attitudes towards the HIV surveillance was the knowledge and views about Africa Centre research activities. This was helpful in identifying how this group of individuals perceived the Africa Centre. Responses from

these participants who had agreed to participate showed they had thorough knowledge about the institute research in general.

Even though these participants regarded themselves as having agreed to partake most of the time, however, at one stage they had refused because they were eligible for this current study as they were randomly selected from the refusal list from the ACDIS:

I have heard that Africa Centre is an institution working with the University of KwaZulu Natal which is more interested in research. That is all I know, nothing much (52 year old male).

A! Don't they check whether things are still the same except when they come when we are tired, we chase them, if we want we ask for love since the wife has passed on. What I know is this thing of finger pricking checking AIDS. I even have a paper confirming I do not have AIDS. I also go to the clinic to check BP and diabetes (63 year old retired teacher).

The way the questionnaire was designed, limited this group to state the reasons of refusing to participate. This was done purposely in order to differentiate the refusal levels from the study sample. If the participant has ever been asked to participate and had agreed, the next question was to measure the way the study was presented to the participants by the Fieldworkers.

4.5.3 PARTICIPANTS WHO CLAIMED THEY WERE NEVER ASKED TO PARTICIPATE

Some participants (17%) who were regarded as refusals were concerned when the study was introduced and explained. These participants claimed to have never been

asked to partake because they are always at work or away and had never seen Africa Centre Fieldworkers. Two participants (90 and 107 year old) who are elderly reported they have never been asked to participate and it is clear that indeed they were never asked as they are always at home. They reported they leave their homes only during pension days or going to the doctor. As a thumb rule, Fieldworkers have to do four visits before they can close the file (bundle) until the next round. It is then impossible that Fieldworkers could not have found them on all four visits.

Again in order to identify whether these participants had in deed never been asked to participate in the HIV surveillance by Fieldworkers, this was compared with their knowledge and views about Africa Centre research as well as recommendations and questions directed to the Africa Centre.

When asked about their views and knowledge about Africa Centre, these participants did not indicate any knowledge about the Africa Centre:

I have heard that Africa Centre… Eish I do not know because they only spoke with a girl, I do not know (107 year female pensioner).

I can only say that Africa Centre wants the breastfeeding mother and they want to know about one's health so that they know what makes a person sick (56 year old female).

I know nothing maybe those who participate know, I only see them counting us and they do not embarrass, they do what they want to do (42 year old female).

When looking at the quotes above, it is very clear that these participants had never had an opportunity to get explanation about the Africa Centre. One may conclude that they indeed had never been asked to participate in the HIV surveillance. The

question therefore is: How come they are viewed as refusals in the ACDIS data base.

4.6 THE FIELDWORKER'S ROLES

The Africa Centre Fieldworkers are working in pairs one female and male when conducting home visits in the HIV surveillance. Fieldworkers visits males and women between the age 15 and 54 and ask them to participate in the HIV surveillance. Since the study asks about sexual behaviour of participants relevant genders will be engaged in interviews.

Finger pricking takes few minutes and Fieldworkers receive thorough training about respect and autonomy of individuals. In the current study where the factors that increase refusal in the HIV surveillance are considered this dimension is included in order to identify whether Fieldworkers had any positive or negative impact on the high rates of refusal.

In the current study participants were asked questions: Was the study properly explained and did you understand why the study is carried out? Did you feel comfortable when Africa Centre visited you? If not what made you to feel comfortable? Were you alone when you were asked to participate in the HIV surveillance?

Some participants revealed they had never been asked by Africa Centre to participate in the HIV surveillance; therefore there is no information available.

Most participants (75%) reported the Africa Centre Fieldworkers explained thoroughly about the HIV surveillance. They also stated when it comes to confidentiality, Fieldworkers were seen a positive light because they asked the

participants aside to either respond to sensitive questions or to give a blood sample for anonymous HIV testing which is the core of the HIV surveillance:

Yes they explained that we were not going to get our results and I was free, alone with my mother in law but that one of finger pricking they asked me aside' 41 year old female).

It's been a while but they explained as you do now, they always explain, I was free, It was me and them only (52 year old male).

*Yes they did explain, what is bad is that when am I getting my results, I wish to know now, I always go to the clinic, I am ready (*34 year old male.)

A few (8.3) participants reported Africa Centre Fieldworkers could not explain why the study was carried out and they were worried about the hastiness of the interviews by some Fieldworkers:

I once asked this lady, I have forgotten her name but I know her, she just told me she has got no time for responding to my questions because there are many other homesteads waiting for her. I told her that when I attended the computer class at the Africa Centre, Buliswa said we must ask when we have questions, this sister just said Buliswa said that because she relaxing and loafing at the office under the air conditioner* (25 year old female).

They failed to explain why they were finger pricking, they just took it from me but I was free alone cleaning my yard (63 year old male).

4.7 CONCLUSION

In this chapter, frequencies, percentages and qualitative results were given and interpreted. The following chapter will cover the discussion with reference to the literature.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter looks at some of the themes that were identified during the data analysis. Themes that will be covered here include, HIV testing and ARVs, assets, and HIV test results. Limitation of the study, recommendation will be incorporated in this section.

The problem statement was: What are the determining factors that make men and women in this community refuse to participate in the HIV and Health surveillance?

This research attempted to identify factors associated with refusal to participate in the HIV surveillance conducted by the Africa Centre in the UMkhanyakude district. The aim of the study was to identify factors that make women and men in the Mpukunyoni community refused to give blood samples for anonymous HIV test

The study aimed to compare reasons of refusing to participate with the characteristics of the researched participants in order to reach conclusions whether certain participants with certain characteristics were more likely to refuse or not. The study also aimed to come up with recommended strategies which can increase the uptake in the HIV surveillance conducted at the Africa Centre

If many participants refuse to give blood samples for anonymous HIV test, this will increase the risk of HIV infection because we will not know whether the infection rate is increasing or decreasing in the Mpukunyoni community. According to Boerma et al,2003, Rice et al.2007,Wambura et al.2007, Zaba et al.2007, HIV surveillances

play a crucial role in understanding the HIV prevalence and incidence which are indicators for HIV treatment and has impact on policy decision making.

This study used a questionnaire to understand the type of refusers and to get their knowledge and views about the Africa Centre with its research activities. The questionnaire also incorporated a section where the participant's attitudes were measured against their knowledge and views about the Africa Centre.

Participants were concerned about different aspects that made them refused to take part in the HIV surveillance.

OBJECTIVE ONE: TO IDENTIFY THE NUMBER OF MEN AND WOMEN IN THE MPUKUNYONI COMMUNITY WHO REFUSED PARTICIPATION

One of the objectives of the current study was to identify the number of individuals refusing to take part in the HIV surveillance. This was an attempt to address reasons making participants refuse to be part in the surveillance conducted by the Africa Centre. Uptake in the HIV surveillance is low according to the findings for the current study.

There were 30 refusals eligible to take part in this study, of those 24 participants were found and interviewed. The 24 we found were represented by 13 male and 16 females who had refused before. The current study reflected 8 males continued saying they will still refuse to take part in the HIV surveillance for different reasons which will be explored in the subsequent section: More work still needs to be done especially to increase the uptake amongst males. This is similar to other studies conducted in different countries where it was found males were more likely to refuse participation in the HIV surveillance (Pool et al: 2009). This study wanted to find out which gender tends to refuse more to blood samples for anonymous HIV testing.

Having more males refusing is an indication that more HIV infections are still going to occur since males are dominant over women in this community. This further suggests males are more ignorant when it comes to HIV and AIDS. These findings are similar to those of Cartoux (2000) who reported women were willing to test for HIV but they needed permission from their husbands or partners.

Likewise Temmerman (2003) reported women who were counselled to tell their partners about their HIV status in Kenya, 11 were chased away from homes and seven were beaten. Regardless of marital status women with partners or husbands reported lack of interest to give blood sample to Africa Centre Fieldworkers.

Reasons for refusals in this community depended on whether a woman has a partner or not. Some woman reported they would not inform their husband about their HIV status if they were tested positive. Increasing more awareness, in this regard is to engage more males in community activities to empower them of the importance of knowing their HIV status. Furthermore, when conducting HIV surveillance, Fieldworkers are encouraged to inform participants of the purpose of the study which is to measure whether the HIV prevalence is increasing or reducing. During the interviews it became apparent some participants did not have information on getting their results.

Several participants were concerned saying the Africa Centre collects information from them and then never came back to report what had been found for each particular study. This is raising a red flag to the Africa Centre community workers because it shows even though, the community is always invited to community events arranged by the Africa Centre, not all participants understands the research conducted.

During interviews in the current study, participants received information about what is being done at the Centre but on individual level and most participants proved they were not fully aware of Africa Centre research. This could be because they always refuse to take part in the HIV surveillance where they could have been given an explanation on what Africa Centre does and does not.

OBJECTIVE TWO: TO IDENTIFY PERSONAL REASONS FOR REFUSING PARTICIPATION IN HIV SURVEILLANCE.

Personal reasons for refusing to part take in the surveillance varied amongst participants. Reasons identified as determining factors to refusals were based on issues like HIV testing and ARVs

It was found participants who were highly educated were likely to refuse participation as they reported that whenever they needed to know their HIV statuses they preferred using their doctors. Refusal pattern was similar for both males and females who had diplomas or degrees and full time employment. These participants were most likely to be the head of the households especially if they were 30 years and above. This often led to these head of households refuse even on behalf of other household members to participate in the HIV surveillance which then increased the number of participants refusing to consent for anonymous HIV testing through finger pricking.

The current study also revealed participants who were already taking ARVs, were more likely to refuse participation. Some participants admitted they were already taking ARVs from the local clinics; therefore participating in the HIV surveillance would mean they are wasting their time. They further suggested Africa Centre must at least encourage them to participate in the HIV surveillance with food parcels

especial for those who are taking ARVs so that they do not take medication on empty stomachs.

OBJECTIVE THREE: TO EXPLORE PARTICIPANTS PERCEPTIONS ABOUT AC RESEARCH AND ITS EMPLOYEES, ESPECIALLY FIELD WORKERS FOR THE HIV SURVEILLANCE.

This study found Field workers do not influence whether participants refused or not. Most participants were positive and reported good conduct by Africa Centre employees especially field workers. Fieldworkers played their role in explaining why the study is carried out. They also managed to keep confidentiality because with the questionnaire where it asked *Were you alone when you were asked to produce a finger prick?* Most participants reported having been alone while those who were with other family members reported having been asked to talk and give blood samples privately.

This suggests trainings on confidentiality home entry and explanation about Africa Centre studies are done correctly. This section also incorporates objective five where the study aimed at improving trust and relationship between the researched participants and Fieldworkers. The study participants did not report any fear or doubt about Fieldworkers. The only negative report was by only two participants who reported Fieldworkers failed to explain why the study was being carried out and they never mentioned anything as evidence due the lack of trust.

OBJECTIVE FOUR: TO OBSERVE THE CHARACTERISTICS OF PARTICIPANTS REFUSING TO TAKE PART.

The study looked at variables like age, gender, setting, marital status and occupation of participants that did not agree to participate in the HIV surveillance.

Gender will be excluded in this section as it is already covered under objective on where a discussion on the number of men and women were discussed.

The study found participants between 30 and 39 years refused more, followed by participants between 40 and 49 years old. When looking at these age categories, these participants are at their most productive years. Moreover, these participants are still sexually active which puts them at more risk of HIV infection. One may therefore conclude if more participants between 30 and 49 years continue refusing, it will be more difficult to know the HIV prevalence and incidence amongst people in this age range. Furthermore HIV infection will continue to rise since these participants are sexually active and yet they refuse to participate in the HIV surveillance.

Since now there is no assurance whether these participants really visit clinics or doctors for HIV tests, it is recommended more campaigns are held to educate community members on the importance of HIV surveillances.

The study also explored settings where more refusals are reported. It was found participants from urban settings constituted high rate of refusals. There was a slight difference between peri-urban and rural setting. This could be, because participants from urban access better health facilities more easily than participants from peri urban and rural setting.

Another variable considered for this study was the occupations of the participants. Unemployed part takers constituted to high rates of refusals followed by full time participants. This suggests unemployed part takers refuse because they are either fatigue and stressed about employment, while full time employed participants use

doctors for HIV tests results in refusing to give further blood samples to Africa Centre field workers.

The community engagement activities to raise awareness and knowledge about AC HIV surveillance, studies focusing on full time employees are suggested.

It was found 25% of women 30 years and above with full time employed reported being busy to give their time to the Africa Centre while 21% of males reported same thing of being busy to attend to research; half of 25% were not married.

The study found marital status in this age category was not the predictor of refusing to participate. When comparing women with men we found 12.5% males of 21% were married.

A similar study which was conducted at antenatal clinics in Senegal, Ghana, Malawi, Zimbabwe, Lesotho and Cameroon found HIV positive people were less likely to participate in HIV surveillances (Reniers & Eaton, 2009, Bärnighausen *et al*.2011). This study further reported refusing to participate did not differ by age. It was found men from urban settings were more likely to refuse HIV tests than women in similar settings (Reniers & Eaton, 2009, Bärnighausen *et al*.2011).

The current study further looked at the employment status for participants and it found 42% of male participants had some source of income as compared to 29% of female participants.

Participants in the current study also reported concerns when being asked about their assets. This was evidence that education on Africa centre activities to the community was essential. The community engagement office team needed to continue with the community engagement to address such concerns in order to put

community members up to speed with the type of data collected from the population. Assets are asked from the community members because it is believed poverty has an impact in the spread of HIV amongst humans. Participants believe when they are asked about their assets, it means Africa Centre will assist if they did not have any of it being asked during home visits.

5.8 LIMITATION OF THE STUDY

The limitation of the study was the sample size which was too small to generalize for the whole population. It became even worse when some of the participants had relocated, died or refused to participation.

Another limitation was the age of eligible participants for the current study. The inclusion criteria was that eligible members had to be 20 years and older. There was not an opportunity to know why participants below the age 20 refuse participation.

5.9 RECOMMENDATIONS

The researcher identified certain issues that could be employed to increase the uptake in the HIV surveillance. Community road shows take place once per year in each ward. In order to enhance the community's knowledge it is recommended that road shows are conducted twice per year per catchment area.

Another recommendation is Africa Centre Fieldworkers receives bi-annual refresher trainings in order to increase their capacity to understand why research is being conducted. They also need to be motivated to be able to explain to participants why particular studies are being conducted.

The third recommendation is on issues of incentives. If participants can be incentivized for participating in the HIV surveillance, the uptake could increase as reported by most participants.

Community advisory board members can also play an important role in educating community at grass root level during community meetings about new studies, changes on studies and other related research activities.

5.10 CONCLUSION

Although the rate of refusals was high in the HIV surveillance, the current study proved if HIV participants are given ample time, respect and humbleness, there could be some form of improvement in the uptake. Looking at the enrolled number of participants for the current study, only one participant refused to participate from all those that were contacted.

Findings of this study indicated it is necessary to explore further some of the issues that have impacted negatively towards the HIV surveillance study. Further interventions need to be introduced within this community to educate and raise awareness about the purpose of the surveillances.

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APPENDIX ONE

AFRICA CENTRE FOR HIV/AIDS MANAGEMENT

17 April 2013

The Africa Centre for Health and Population Studies
Mtubatuba
KwaZulu Natal
South Africa

Dear Sir/Madam

RE: Intention to conduct a research project in the Mpukunyoni DSA, Mtubatuba.

Miss Ncengani Mthethwa, a Master of philosophy student in HIV and AIDS Management (Student Number: 17388554), at the Africa Centre for HIV/AIDS Management at Stellenbosch University in South Africa Centre intends to conduct a research on selected participants in the HIV Surveillance on the ` Factors affecting refusal to test for HIV in UMkhanyakude district, Mtubatuba, KwaZulu Natal, South Africa'.

The aim of this study is to identify factors that make men and women of the Mpukunyoni community refuse HIV testing in order to devise strategies that could increase the HIV uptake in the HIV surveillance so that research participants would be able to access antiretroviral treatment as soon as they become eligible. Participants who have refused HIV testing in the AC HIV surveillance between 2010 and 2012 will be randomly selected from the existing data to partake in the study. A questionnaire (guide) with five themes will be used to identify factors that make men and women of the Mpukunyoni community refuse HIV testing. All the data collected from this study will be safely stored to ensure that no other person has access to it. The research is primarily academic but the results of the study will be submitted to the Africa Centre for Health and Population Studies. The student will apply for Ethical Clearance from the University in July 2013.

We therefore kindly request permission for Ncengani Mthethwa to carry out this study in your research. The study will run from August 2013 until January 2014. Feel free to contact us if you have any further questions in this regard.

Kind Regards,

Burt Davis
Lecturer
Africa Centre for HIV/AIDS Management
STELLENBOSCH UNIVERSITY | Private Bag X1 | Matieland 7602 | RSA
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APPENDIX TW0

AFRICA CENTRE
FOR HEALTH AND POPULATION STUDIES

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

Burt Davis
Lecturer
Africa Centre for HIV/AIDS Management
STELLENBOSCH UNIVERSITY

Dear Dr Davis

I acknowledge your letter dated 17 April highlighting the proposed research by Miss Ncengani Mthethwa, a Master of philosophy student in HIV and AIDS Management (Student Number: 17388554), at the Africa Centre for HIV/AIDS Management at Stellenbosch University . She currently is a member of staff at the Africa Centre, within the Community Engagement Unit, and her proposed research on selected participants in the Afriac Centre's annual HIV Surveillance to explore why adults refuse to participate in a HIV surveillance round.

I fully support this proposal, which fits in well with her current work commitments and the overall research strategy of the Africa Centre for Health and Population Studies. I will provide whatever support she needs locally for this research.

Kind regards

Marie-Louise Newell MB MSc PhD FMedSci
Professor of Health & Population Studies UKZN
Professor of Paediatric Epidemiology, UCL, London
Director – Africa Centre for Health & Population Studies

Postal: PO Box 198, Mtubatuba 3935, South Africa
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Email: info@africacentre.ac.za
Web: www.africacentre.com

Patron: HRH King Goodwill Zwelithini

wellcome trust

APPENDIX THREE

28 October 2013

The Chair
Biomedical Research Ethics Committee
University of KwaZulu-Natal
Govan Mbeki Building
Westville Campus
Durban
4000

Dear Professor Wassenaar

Re: Request for Reciprocity (HS957/2013)

This letter presents a request for reciprocity for a MPhil study entitled: *Factors associated with refusal to participate in the HIV surveillance in rural KwaZulu-Natal, South Africa* under the supervision of Prof Elza Thomson from the Department of Economics and Management Sciences at Stellenbosch University, and co-supervision of Prof Marie Louise Newell at the Africa Centre for Health and Population Studies. The follow-up with participants to determine the factors affecting refusals are administered as part of the work already undertaken by the Community Engagement Unit of the Africa Centre and will not require additional funding.

The protocol has undergone full review by the institutional review board of the Human Research Ethics Committee (Humanities) at Stellenbosch University and received full ethical approval on 24 October 2013. The study was also presented in detail to the Community Advisory Board (CAB) in their monthly meeting on the 2^{9th} August 2013 at the Africa Centre for Health and Population Studies. Since it is the intention of the MPhil student to conduct the field work at the Africa Centre for Health and Population Studies we make a request for the Humanities approval for this study to be granted reciprocity with the Biomedical Research Ethics Committee (BREC).

The protocol and letters of approval from both the Humanities and CAB are attached with this letter.

Kind Regards

Ncengani Abigail Celani Msane (Mthethwa)
Africa Centre for Health and Population studies
nmthethwa@africacentre.ac.za

APPENDIX FOUR

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

RESEARCH OFFICE
BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 260-4609
Email: BREC@ukzn.ac.za
Email: BREC@ukzn.ac.za
Website: http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx

25 November 2013

Ncegani Abigail Msane
Africa Center for Health and Population Studies
nmthethwa@africacentre.ac.za

Re: Request for Reciprocity (HS957/2013)
Study Title: "Factors associated with refusal to participate in the HIV surveillance in rural KZN, South Africa".

I wish to advise that your letter dated 11 November 2013 to the Chair of the Biomedical Research Ethics Committee (BREC) requesting reciprocity for the above study refers.

The chair has granted reciprocity to the University of Stellenbosch's ethics approval dated 25/10/13.

This approval will be noted at the next Biomedical Research Ethics Committee meeting to be held on 10 December 2013.

Yours sincerely

Ms A Marimuthu
Senior Administrator: Biomedical Research Ethics Committee

APPENDIX FIVE

28 October. 2013

Biomedical Research Ethics Committee
University of KwaZulu-Natal
Private Bag x7
Congella 4013

Dear Sir/Madam

Project title: Factors associated with refusal to participate in HIV surveillance in the rural KwaZulu Natal, South Africa

This serves to advise that the above-mentioned study was presented in detail to the Africa Centre Community Advisory Board on 29th of August 2013.

The CAB members asked questions about a wide range of aspects relating to the study. The questions and comments were adequately addressed by the study presenter Ms Ncengani Msane Mthethwa. The CAB members carefully considered the benefits of the study to individual participants and the community as whole. They encouraged the Community Engagement Unit to look deeply on the causes of refusals and they and gave permission that the study is very good for the community of Mpukunyoni.

It is from this premise that the CAB hereby unconditionally grants permission to the Africa Centre for Health & Population Community Engagement Officer, Ms N Msane Mthethwa to conduct the proposed study.

Yours sincerely

CAB Chairperson

Mandla B. Zulu

CAB Secretary

Hlengiwe Ndlanzi

Management Committee Chairperson:
Members:

Postal: PO Box 198, Mtubatuba 3935, South Africa **Physical:** Africa Centre, R618 en route to Hlabisa, Somkhele
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APPENDIX SIX

Factors Associated with Refusal to participate in the HIV surveillance consent form and Information Sheet. Proposal #HS957/2013

INTRODUCTION

My name is Ncengani Mthethwa Msane from the Africa Centre. I am currently studying at Stellenbosch University for MPhil (BAHSSc, PDM). As part of my academic requirements I am expected to conduct a research in this community. You are asked to participate in a research study called 'Factors associated with refusal to participate in the HIV surveillance area". This study will be conducted by the Africa Centre for Health and Population Studies which is the research institution situated at Somkhele, under Mpukunyoni area. I will be conducting this study with the Africa Centre Director Marie Louise Newell (MB MSc PhD fMedSci) and Professor Elza Thomson (), from the Africa Centre for HIV and AIDS Management at Stellenbosch University. You were selected as a possible participant in this study because you are one of the participants who have been randomly picked up by the computer programme to participate in this study and because you have previously indicated that you do not like to take part in the HIV surveillance when the Africa Centre Fieldworkers visited you in the past months.

PURPOSE OF THE STUDY

We are always concerned when people do not, or no longer, want to participate in our research, and we now want to understand the reasons why men and women in this community refuse to participate in our HIV and Health surveillance in order to devise strategies that could increase participation in the surveillance.

As part of the HIV surveillance, as well as asking you questions about your health, and sexual partnerships, we also ask you to give us a small finger prick sample which we then take to our laboratory in Durban. There we look at all the samples, which no longer have a personal name with them, to see whether we can detect HIV. The results from all the tests that we do on all the people who participate in our surveillance helps us to understand how much HIV there is in the community, where in particular there is a problem, but most importantly it helps us to show the impact of antiretroviral therapy on how many new HIV infections there are in this area, and other things such as how much HIV treatment has caused the number of deaths to go down in this area.

For this work to continue to be reliable, continued participation of all adults in the community is important, and thus we need to know what reasons people have for no longer wanting to participate our research, and we now want to understand the reasons why men and women in this community refuse to participate in our HIV and Health surveillance in order to devise strategies that could increase participation in the surveillance.

With this study we want to understand the factors that make men and women in this community refuse to participate in the HIV surveillance in order devise strategies that could increase the HIV uptake in this community so that the research participants

can be informed about the HIV prevalence in this community to enable them to take special precautions regarding their health.

PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

- We will request that you give us 30 to 45 minutes of your time to talk to us.
- We can either do the interview now, or we can come back at a time that is more convenient to you – it is up to you to let me know what you would prefer.
- We will ask you to share with us your feelings and ideas about the Africa Centre and participating in the HIV surveillance.
- We would also like you to share with us whether you have participated before. We would like you to share with us what is it that you would like us to share with the Africa Centre management in order to increase participation in the surveillance in this community and any other information that you like us to know.

Answers given to us will be completed into these forms.

POTENTIAL RISKS AND DISCOMFORTS

There is no physical harm to the participants. This study is about HIV refusal to participate in the HIV surveillance and HIV topic can be a sensitive issue to some people, some participants may not be comfortable to talk about this topic.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

This study aims to helps us understand how much HIV there is in this community, where in particular there is a problem, but most importantly it helps us to show the impact of antiretroviral therapy on how many new HIV infections there are in this

area and other things such as how much HIV treatment has caused the number of deaths to go down in this area.

PAYMENT FOR PARTICIPATION

Participants will be visited at their homes and we will try by all means to find them at their homes, therefore there will be no payment or compensation towards participation.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with the study participants will remain confidential and will be disclosed only with their permission or as required by law. .. The forms for all the qualitative studies at the Africa Centre are locked up in the optiplans in the data centre for the course of the study for three years, after that the documents and all the forms are taken to the metro file where then, they get destroyed.

Findings of this study will be shared with the community but we will not give names and answers but only the numbers who agreed and those that refused to participate and the reasons of why certain participants refused participation in the HIV surveillance.

WHO ELSE IS TAKING PART IN THIS STUDY?

Participants include 15 men and 15 women between 20 and above residing in KwaMsane Township, KwaMsane reserve, Gunjaneni and DKD and they must be regarded as full resident members of the households in these areas. They should be:

- Those that has refused talking with AC staff in the last three rounds
- Those that persistently refused responding to AC sexual questions for more than three times in the previous rounds

- And those that did not refuse but parents, guardians or partners refused on behalf of them.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact the following people:

Professor Elza Thomson (Supervisor)

University of Stellenbosch

0824946920

Email- elzathomson@gmail.com

Mr Mduduzi Mahlinza (Community Engagement Manager)

Africa Centre for Health and Population Studies

035-5507500

Ncengani Msane (Mthethwa) (Investigator)

Africa Centre for Health and Population Studies

035-5507579

Alternatively you may use the Africa Centre Community Engagement Office toll-free number below during office hours:

(0800-203695)

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me……...by ……in isiZulu and I am in command of this language. I *was* given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study and I have been given a copy of this form.

_____

Name of Subject/Participant

_____

Name of Legal Representative (if applicable)

_____

_____

Signature of Subject/Participant or Legal Representative **Date**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the participant]* and/or [his/her] representative _____ [*name of the representative]. [H*e/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in IsiZulu.

_____ _____

Signature of Investigator Date

APPENDIX SEVEN

Copy of selected cases

DSID	Sex	DoB	Area Name	BSID	Random
HRMW-B	FEM	1972/11/20	Gunjaneni	56661	-2128963734
GTVG-S	FEM	1923/01/04	Gunjaneni	65518	-2115906109
HVDP-F	FEM	1971/08/04	Gunjaneni	73139	-2142767678
KSZM-H	MAL	1959/10/29	Gunjaneni	11987	-2071273882
KZKX-S	MAL	1964/12/06	Gunjaneni	55188	-1975401670
BMRD-D	MAL	1972/04/07	Gunjaneni	65799	-2097141362
HWDW-L	FEM	1984/09/14	KwaMsane (Isigodi)	15230	-2147336393
GSTS-K	FEM	1981/09/18	KwaMsane (Isigodi)	31234	-2111430217
SVBR-S	FEM	1988/08/30	KwaMsane (Isigodi)	45512	-2115834587
GLNJ-P	FEM	1967/11/29	KwaMsane (Isigodi)	66391	-2115151881
PTVZ-C	MAL	1988/07/09	KwaMsane (Isigodi)	15273	-2118533580
RKCL-Z	MAL	1979/09/25	KwaMsane (Isigodi)	31242	-2129144915
GYFW-S	MAL	1974/08/10	KwaMsane (Isigodi)	60064	-2138442144
JXDJ-M	MAL	1986/07/01	KwaMsane (Isigodi)	66339	-2137851906
CNRX-J	FEM	1906/04/23	KwaMsane (Township)	26569	-2125573073
LWJG-R	FEM	1967/03/13	KwaMsane (Township)	41375	-2081735656
DFBX-W	FEM	1957/10/10	KwaMsane (Township)	51421	-2079638891
JCGN-X	FEM	1959/10/15	KwaMsane (Township)	61270	-2111208776
HXFW-R	MAL	1961/09/20	KwaMsane (Township)	31349	-2099776089

LMGH-V	MAL	1950/05/28	KwaMsane (Township)	56486	-2147290191
JPZD-Q	MAL	1950/01/08	KwaMsane (Township)	61239	-2111643192
GWXM-D	MAL	1958/03/17	KwaMsane (Township)	61280	-2144076541
NGSP-Z	FEM	1974/12/02	Ndlovu Village	18358	-2133267575
FLWD-T	FEM	1983/07/24	Ndlovu Village	18830	-2125536108
PLFD-D	FEM	1976/06/23	Ndlovu Village	19237	-2103768263
BGHC-J	FEM	1968/12/08	Ndlovu Village	19494	-2134878294
SCCM-R	MAL	1976/01/04	Ndlovu Village	18421	-1870105079
PRTJ-C	MAL	1989/06/20	Ndlovu Village	18454	-2075586935
SFFV-M	MAL	1977/12/14	Ndlovu Village	19451	-2011511635
SCVT-Y	MAL	1981/06/20	Ndlovu Village	19539	-1994915763

APPENDIX EIGHT

Factors Associated with Refusal to Participate In the HIV Surveillance Questionnaire (FARTPQ) V.1, 2013, Proposal #: HS957/2013

Form completion date | Y | Y | Y | Y | M | M | D | D | Staff code | | | |

BSID | | | | | | **DSID** | | | | | | | IZigodi/Area | |

Participants Name | |

1. Demographics

Sex Male ○ Female ○

Age | | | years

Marital Status | |

Occupation | |

Highest Education | |

Country of birth | |

2. Knowledge and Views about Africa Centre

As a resident of this community what can you say about Africa Centre research conducted in this community?

3. Attitude to HIV surveillance

3.1	Have you ever been asked to provide a finger prick specimen within the HIV surveillance by Africa Centre fieldworkers?	Yes○→ Q3.2	No○→ Q4
3.2	If Yes, did you agree to participate?	Yes○→ Q3.4	No○→ Q3.3
3.3	If No, what has prevented you from participating?		

3.4 Was the study properly explained and did you understand why the study is carried out?

3.5 Did you feel comfortable when the Africa Centre visited you? If not what made you to feel uncomfortable?

3.6 Were you alone when you were asked to participate in the HIV surveillance?

4. Recommendations

What do you think we should know in order to encourage the community members to participate in the HIV Surveillance at the Africa Centre?

5. Any other Questions or Comments?

Are there any other questions or concerns you have regarding HIV surveillance conducted by the Africa Centre?

End of Questionnaire