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“If you seek, you know you will find and if you find  
you have cancer, why do you seek?”  
KNOWLEDGE AND PRACTICES  
REGARDING CANCER SCREENING AND  
PREVENTION IN CATO MANOR

Lilly Hennessey  
*SIT Study Abroad*

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"If you seek, you know you will find and if you find you have cancer, why do you seek?"

KNOWLEDGE AND PRACTICES REGARDING CANCER SCREENING AND PREVENTION IN  
CATO MANOR

Lilly Hennessey

School for International Training

Community Health and Social Policy Fall 2018

Advisor: Christine McGladdery

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This project is dedicated to my aunt, uncle, and the countless others who have fought cancer.

## ABSTRACT

The incidence of cancer continues to increase in South Africa, creating a serious concern for public health. There are currently several cancer awareness programs operating in the Durban area, but little is known as to whether they are having a positive impact on communities. This project aimed to understand the knowledge and practices regarding cancer screening and prevention in Cato Manor, KwaZulu-Natal. In doing so, it assessed the effectiveness and knowledge of current programs which work to increase cancer awareness.

This study used a mixed methodology approach. Surveys were given to 30 residents of Cato Manor to gain a quantitative understanding of cancer knowledge and screening practices in the community. Focus group discussions and one-on-one interviews were then conducted with survey respondents to gain a deeper, more qualitative understanding of lived experiences and the relationship between cancer knowledge and practices.

In general, cancer awareness programs were not commonly recognized among respondents and screening exam use was not common. Many people still believe cancer is not a problem for the community, but the vast majority claimed they worry about cancer. Programs and policy must be created to increase use of screening exams and move cancer awareness programs into townships like Cato Manor.

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## INTRODUCTION

In response to the increasing burden and growing concern of cancer in public health, dozens of cancer awareness and prevention programs have been created in the greater Durban area. However, it can be extremely difficult to measure the impact of these programs on the general population. Asking community members of a township whether they have heard of a collection of these awareness programs can act as a tool to gain insight as to whether the programs have impacted their lives. The effectiveness of cancer awareness programs can also be measured by discovering how knowledge and behavior regarding cancer screening have changed over time. However, this can only occur when there is a set of baseline data which reflects the practices of community members. Successful interventions also require information about the community they target in order to understand what could work well and what might need to change. Due to this, the objectives of this study were to:

- Understand the knowledge regarding cancer screening and prevention in Cato Manor, KZN and how that knowledge translates into participating in cancer screening tests.
- Gain insight on the effectiveness of current cancer prevention programs by asking participants whether they have heard of a collection of those programs.



## CONTEXT

Cancer is the second leading cause of death worldwide and was responsible for an estimated 9.6 million deaths in 2018. Globally, about 1 in 6 deaths is due to cancer (*Cancer*, 2018). Cancer kills more people than HIV, TB, and malaria globally (Jordaan et al 2016, p. 1). It is clear the incidence of most if not all forms of cancer are continuing to increase. For example, the incidence of breast cancer has increased “more than 50% from 1980 to 2010 globally” (Institute for Health Metrics and Evaluation 2011 in Phaswana-Mafuya & Peltzer 2018, p. 1496).

Recently, the burden of cancer has shifted to low and middle-income countries. Low and middle-income countries account for roughly 57% of cancer cases and 70% of cancer deaths (Torre 2015, p. 88; *Cancer*, 2018). South Africa itself has higher rates than the global average for a number of different types of cancer. In 2013 there were an estimated 101.56 cases of cancer per 100,000 women and 88.43 cases per 100,000 men in South Africa. The age standardized incidence rates for cervical cancer was 31.7 per 100,000 persons in South Africa compared to 14.0 per 100,000 persons globally in 2012 (Denny & Kuhn 2017, p. 190).

Early detection and treatment of cancer are critical to reduce morbidity (Krombein & De Villiers 2006, n.p). If cancer is detected early, it is less likely to have metastasized to other tissues and is easier to treat, improving patient outcomes (*Breast Cancer*, 2018). The five-year survival rate for stage I invasive cervical cancer is estimated to be between 80-90% with appropriate treatment. If the cancer is not detected and has progressed to stage IV, the survival rate is less than 15% (De Abreu 2014, p. 12). Although it is clear that early detection and screening are crucial in reducing the burden of cancer, the practices are not fully implemented in South Africa. Cases are often diagnosed late, causing the morbidity to be higher than necessary. For example, one 2008 national survey found only 15.5% of women in South Africa had ever underwent a breast cancer screening (Peltzer & Phaswana-Mafuya 2014, p. 2474).

In October of 2018, KwaZulu-Natal Health Department launched a provincial mass cancer screening program at Greys Hospital in Pietermaritzburg, demonstrating the relevance of the topic (KZN Launches, 2018). One study found KwaZulu-Natal performs the most cervical smears of all the provinces, but also finds the greatest percentage of both low and high-grade cancer lesions in its patients (Denny & Kuhn 2017, p. 191). The burden of cancer, specifically cervical cancer, could be greater in KwaZulu-Natal for a number of reasons. One of those reasons is likely that cancer rates are higher in HIV-infected individuals (*HIV Infection*, 2017). KwaZulu-Natal has the highest rate of HIV of South African provinces, making cancer a pressing public health issue in this province particularly.

## LITERATURE REVIEW

This literature review is organized into the following five subcategories to provide an organized overview of existing work in related and relevant topics: the value of cancer screening and prevention; barriers to screening and prevention; assessing cancer risk factors; the relationship between HPV and cancer; the relationship between HIV and cancer; and current programs and policy.

### *The Value of Cancer Screening and Prevention*

Screening tests differ from diagnostic tests in that they are performed before the onset of symptoms. They aim to detect disease at an early stage before symptoms appear. Most screening tests cannot influence whether someone will become ill, and therefore are not considered preventative. Meanwhile, cancer prevention is divided into three subcategories to better distinguish the form of prevention. Primary prevention works to keep the cancerous process from ever happening. It aims to limit disease incidence through controlling causes and risk factors (White et al 2013, p. 1). After primary prevention has failed, secondary prevention works to discover and control cancer as early as possible, preventing it from spreading to other tissues and becoming more severe. Screening, along with early detection and effective treatment, are forms of secondary cancer prevention (Spratt 1981, n.p.). Finally, tertiary prevention works to reduce the morbidity and symptoms in people with cancer. This type of prevention can include understanding and addressing psychological effects of cancer treatment (Jacobsen & Andrykowski, 2015).

While there have been some international studies, little research has been done on screening behavior of South African women specifically, as well as men (Krombein & De Villiers 2006, n.p.). One study found women in South Africa who had at least one Pap smear in their lifetime had 70% lower odds of developing cervical cancer when

compared to their counterparts who had never had a Pap smear (Hoffman et al 2003, n.p.). After implementing a nationwide screening program, Iceland reduced its cervical cancer mortality by 84% (Denny & Kuhn 2017, p. 191). This shows how effective screening tests can be in reducing the burden of cancer when fully utilized.

### *Barriers to Screening and Prevention*

Cancer screening services are still not fully utilized by the majority of the population of South Africa for a number of reasons (Bradley et al 2004). Studies have found education, employment, age, and socioeconomic status, as well as having medical aid, private health insurance and chronic conditions are associated with getting cancer screening tests in South Africa (Phaswana-Mafuya & Peltzer 2018; Krombein & De Villiers 2006). Other factors which may be barriers in receiving cancer screening and prevention include money, time, trust in the medical system, fear of being diagnosed, limited availability of diagnostic machines, poor transportation infrastructure and stigma associated with the disease.

### *Assessing Cancer Risk Factors*

Extensive research has been done on describing factors which may contribute to getting cancer. Some of the most effective programs which aim to prevent cancer have focused on reducing risk factors. Due to these programs, it is now common knowledge that activities such as smoking increase one's risk of getting cancer. Some of the most influential risk factors for cancer include smoking, obesity, lack of physical activity, and infection (Torre 2015, p. 95). In lower income countries, an estimated 20% of cancers are due to infections, such as Hepatitis B, Hepatitis C and HPV. An estimated 22% of worldwide cancer-related deaths are caused by smoking. Another 10% are due to

obesity, a poor diet, lack of physical activity, and consuming alcohol. Finally, roughly 5 to 10% of cancers are due to genetics (Herbst 2018, p. 1).

Due to lasting effects of the injustices of the apartheid system and current social and economic inequalities, black South Africans have previously, and often still lack optimal access to medical services, including cancer screening services and knowledge of prevention strategies (Francis et al 2010; Pilay 2002). White South Africans tend to present with cancer at earlier stages, coloureds and Indians at intermediate stages, and black South Africans at later stages of disease severity, showing that screening differs among racial groups (Krombein & De Villiers 2006, n.p). Previously, it had been found that over 60% of black South African women had never had a Pap smear (Peltzer, 2001). One study conducted in Cape Town found black South African women have a higher risk of developing cervical cancer compared to the other three racial groups (De Abreu 2014, p. 92). Another study concluded black women in South Africa have a 1 in 34 risk of getting cervical cancer. That risk was 1 in 93 for white South African women (Redelinghuys & Van Rensburg, 2004 in De Abreu 2015, p. 11). There are a number of factors which may be contributing to this health disparity. It shows, however, that race can be considered a risk factor for developing cancer in South Africa.

### *The Relationship between HPV and Cancer*

Human papillomavirus (HPV) infections affect the onset and progression of cervical cancer. The greatest risk factor for contracting cervical cancer is a chronic and persistent HPV infection (Ghebre et al 2017, p. 34). The Information Centre on HPV and Cancer claims "HPV causes virtually 100% of cervical cancer cases" (Bruni et al 2017, p. 34). HPV vaccination has the potential to reduce the incidence of cervical cancer by at least 70 to 80% in those vaccinated. Since administering the HPV vaccine to girls in Australia in 2006, there has been a reduction in HPV cases among unvaccinated women,

suggesting herd immunity<sup>1</sup> may be possible with enough vaccine coverage in a population (Denny & Kuhn 2017, p. 193).

The Medicines Control Council of South Africa approved two HPV vaccines in 2008 (Richter 2015, p. 1). In 2014, the National Department of Health launched the national HPV vaccination program which provided the vaccine to female Grade 4 learners in public schools across the country (Tathiah & Naidoo 2015, p. 1). However, HPV rates remain high among most population groups in South Africa, increasing the burden of cervical cancer.

### *The Relationship between HIV and Cancer*

Since the identification of AIDS in 1981, cases of cervical cancer have increased in South Africa (Ghebre et al 2017, p. 101). Women with HIV/AIDS are more likely to have HPV, and therefore are at increased risk for developing cervical cancer (Ghebre et al 2017, p. 102). Additionally, cancer progresses faster in patients with HIV (Jordaan et al 2016, p. 3). The South African Department of Health advises, "Pap smear screening should be done for all women at least 18 years of age at initiation of antiretroviral therapy (ART) and once every 3 years following a negative Pap result" (South African Department of Health 2010, p. 3).

However, HIV/AIDS does not only affect cervical cancer. In 1981, Kaposi's sarcoma became recognized as a hallmark of AIDS (Ghebre et al 2017, p. 101). The third most common type of cancer in black South African men and the fifth most common type in black women is Kaposi's sarcoma, suggesting that the prevalence of HIV plays a significant role in cancer in the country (Herbst 2018, p. 3). Soon, Non-Hodgkin

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<sup>1</sup> When enough of a population is immune to a disease, usually through vaccination, to the point where infectious disease cannot spread. This allows those who are not vaccinated and are vulnerable to the contagion to be protected from the disease. Herd immunity is usually achieved at 90% vaccination.

lymphoma, as well as cervical cancer followed as AIDS-defining illnesses (Centers for Disease Control and Prevention 2002 in Ghebre et al 2017, p. 101).

### *Current Programs and Policy*

Methods for prevention and detection of cancer have been well-defined since the 1960s, yet effective implementation of policy still lacks. The South African National Department of Health implemented the South African Cervical Cancer Screening Program, a screening program which allows women over the age of 30 to have a free Pap smear every 10 years (Department of Health 2002, p. 4). However, some claim the program has not been fully implemented and that not all women know the program exists (Jordaan et al 2016, p. 1). In 2011, the HIV Counseling and Testing campaign was launched. The campaign focused on encouraging people to know their HIV status and access counseling and treatment (Jordaan et al 2016, p. 1). Part of the campaign encouraged any woman who tested positive for HIV to have a Pap smear. In 2014, the South African National Department of Health implemented a school-based HPV vaccination program for girls (Jordaan et al 2016, p. 4). For the first dose campaign, 16,495 schools were visited, bringing national coverage to 92.6% in that age group (Jordaan et al 2016, p. 4). However, it will take decades until the effects of this program are known.

### *Role of CANSA in KwaZulu-Natal*

The Cancer Association of South Africa (CANSA) has launched several programs in the Durban area, working to increase cancer awareness, detection and screening. Recently it began a partnership with the KwaZulu-Natal Health Department to increase cervical cancer screening in the province. This partnership included the 2018 Umdlavusa Pap Smear Drive, which works to raise awareness of cervical cancer, provide free Pap

smear screening to those eligible, and educate women about prevention while encouraging them to have regular pap smears.

CANSA additionally sends mobile clinics throughout Durban to conduct screening exams, on top of hosting several fundraisers and awareness programs including SunSmart, Shavathon, Relay for Life, Hollard DareDevil Run, CANSA Active, Sanlam Cancer Challenge, and Cuppa for CANSA (CANSA 2018). SunSmart is a seasonal campaign which works to increase awareness of skin cancer and encourage people to be cautious in the sun throughout the year. Shavathon and Relay for Life both are fundraising events which simultaneously work to show solidarity with those affected by cancer and increase awareness. Hollard DareDevil Run is a race which aims to raise awareness about prostate cancer. CANSA Active is a fundraiser which encourages participants of various marathons and other races to raise money for cancer. The Sanlam Cancer Challenge is the largest amateur golf tournament in South Africa. It occurs annually to raise funds and awareness. Finally, Cuppa for CANSA encourages people have an event during which they share a drink with friends and family, socialize, and raise money for cancer.



## METHODOLOGIES

### Methodology Overview

Both quantitative and qualitative data were collected through 30 surveys, three focus groups, and two one-on-one interviews. Qualitative and quantitative methods can be extremely effective when used together. Quantitative data were collected through surveys in order to learn how common certain behavior and beliefs were in the study population. The larger sample size which can be obtained through surveys increases the reliability of data and allows statistical tests to be run. Those tests can look for correlations and associations between dozens of different factors.

Qualitative methods helped to increase understanding of cancer knowledge, since it allows for longer, more in-depth questions and answers. According to Brikci and Green (2007), qualitative methods allow the researcher to have access to how people talk to each other, showing different power structures and how some react to the views of others. Focus groups allow non-verbal forms of communication such as facial expressions, body language, and social dynamics of the group to be seen while hearing stories of personal experiences (Ayuen 2015, n.p.). Focus groups were used to see how cancer is discussed in a group setting. When focus group discussions were geared toward learning what the community does and believes, interviews were used to discuss what an individual does and believes. Interviews were used to ask slightly more personal questions which should not be discussed in a focus group, like whether a participant knows someone who has had cancer, or whether it is a worry of theirs. Therefore, a mixed-methods approach was the best way to both gain insight toward what knowledge of cancer screening and prevention is like in Cato Manor and why that may be.

### Sampling Plan

After revising the survey based on responses from a pilot study, data were collected in Cato Manor. Cato Manor is a township approximately 7 km from the center of Durban, KwaZulu-Natal. Residents of Cato Manor are 97% black African and 82% Zulu-speaking. The average income in Ward 29, the ward where Cato Manor lies is approximately R 14,600. An estimated 78% of the population of Ward 29 have completed Grade 9 or higher and 46.3% have completed Matric or higher (Municipal Elections, 2016).

Most of the participants were recruited through social networks and snowball sampling. The survey was administered to residents of Cato Manor who were over the age of 18. At each of the focus group discussions, a translator was available. All participants went through the informed consent process. They were informed of their rights to confidentiality, anonymity, and voluntary participation.

## Survey Procedure

Surveys were administered to 30 participants in group settings in local homes. The survey was composed of 29 questions. Ten questions gathered demographic information, such as age, highest level of educational attainment, and employment status. Two questions asked about sources of cancer knowledge. Five questions were then used to assess cancer knowledge. Eleven questions attempted to understand participant beliefs and experiences with cancer. One question asked about knowledge of current cancer awareness programs. A copy of the survey is in Appendix 1.

Participants of each of the three focus group discussions were asked to fill out the survey prior to the discussion. Non-focus group participants were given the survey in groups with other participants to ensure anonymity. Before distributing the survey, every question was explained to the group. The participants were informed that if they felt uncomfortable answering personal questions about their experience with cancer, they should skip four specific questions. Informed consent was explained to each

participant before they were given a survey and no names of survey respondents were collected.

It was at times difficult to find enough community members to complete the survey. One of the greatest challenges was the fact that surveys were administered in English, but not every interested resident of Cato Manor spoke fluent English. A translator had to always be available to participants and was used to explain the meaning of survey questions at times. It was also clear that some participants did not know the meaning of certain medical terminology, such as HPV vaccine or mammogram.

## Focus Group Procedure

After administering surveys to focus groups, respondents participated in a facilitated discussion about the topics from the survey. Eighteen informants participated in one of the three focus group sessions. Group discussions were semi-structured in the sense that they were loose and fluid, allowing participants to be free to discuss related concepts. Open-ended questions were used to guide the discussion. The audio recordings for focus group discussions were taken after gaining consent from all participants.

## Interview Procedure

Two residents of Cato Manor were interviewed about cancer screening and prevention to gain a deeper understanding of the topic. Both of these individuals completed the survey prior to their interview. Interviews were held in participant houses and public areas, though participants were informed that there were other locations available if desired. Interviews resembled everyday conversations and attempted to make the individual feel comfortable. They differed from everyday conversations in the

sense that the interviews were guided, focusing on cancer-related topics. The audio recordings for interviews were taken after gaining consent from all participants.

## Procedure for Statistical Analysis

Pearson's Correlation and Spearman's Rho tests were used to measure the strength of association between two variables. Fisher Exact and Chi Square Tests were used to determine whether two variables were associated in a significant way in the study population. Finally, T-tests were used to determine whether a subgroup of the population produced statistically significant answers compared to the population as a whole.

## Limitations and Bias

The greatest limitation in this study was the sample size (N=30), due to time constraints. Suggestion bias through survey question phrasing was possible, as well. Some participants didn't understand certain terms, such as "HPV vaccine" or "colonoscopy," which may have affected their answers. The survey relied on the fact that if a participant has had the HPV vaccine or a colonoscopy, they would know what the term means. Similarly, it is possible a participant may have had a blood pressure check but did not know the term, and therefore, did not record it. Prior to the survey, respondents were informed that men would not have had the HPV vaccine to reduce confusion.

Some survey questions relied heavily on memory, such as the questions which asked whether participants had specific screening exams and where people get their

knowledge of cancer. Therefore, recall bias is possible. For example, two female participants who were the same age and both stated that they attended Penzance Primary completed the survey. One participant claimed she learned about cancer in primary school when the other did not. This form of inconsistency occurred in participants from Rippon Primary (one said they learned when three didn't), Nsimbini Primary (two claimed they learned when one didn't), and Chesterville Secondary (four claimed they learned when one didn't). However, it is important to note curriculums change and may vary among classes, and none of the participants in these examples were the same age.

## ETHICS

The study was anonymous, confidential, and voluntary. No participants were forced or coerced to answer any questions which they did not wish to answer. Participants were allowed to skip questions or leave the room if necessary. The study was approved through the Local Review Board on October 22, 2018. Participants were allowed to withdrawal consent up until November 23, 2018.

Participants were first told the purpose of the study, then had their rights of anonymity, confidentiality, and voluntary participation explained. Data were stored on a password-protected computer without any identifiers. The only data which could contain identifying information is the survey question which asked whether a participant or a family member has had cancer. However, that data was used solely for statistical analyses and is not included in the final write-up. Names of survey respondents were not collected, and survey responses were not linked to focus group or interview responses to protect anonymity. Audio recordings of interviews and focus groups were deleted after submitting the final project and kept on a password-protected phone. Data were also deleted after submitting the final project.

The study participants were residents of Cato Manor over the age of 18. No minors or known vulnerable populations were allowed to participate in the study. Each participant's place of employment and institutional affiliation was unknown. Prior to taking the survey or participating in focus group discussions or interviews, participants were informed that they could leave at any time. Before taking the survey, participants were told to skip four survey questions which may cause emotional distress if there was a chance they may feel stress when discussing their personal history with cancer. Counseling resources were available for any participant who expressed that they felt distress. No participants were asked to disclose their HIV or other sexually transmitted infection status if they did not want to. Prior to the survey, each question was

thoroughly explained. At each survey session, a translator was available to answer questions, since the survey and discussion sessions were in English.

Focus groups and interviews were held in participant homes, local public areas, and the office of the sponsoring institution, the School for International Training. Respondents were allowed the option of participating interviews in another venue if so desired. A copy of the final project was given to participants who asked to receive it.

## FINDINGS

### Overview of Cancer in the Community

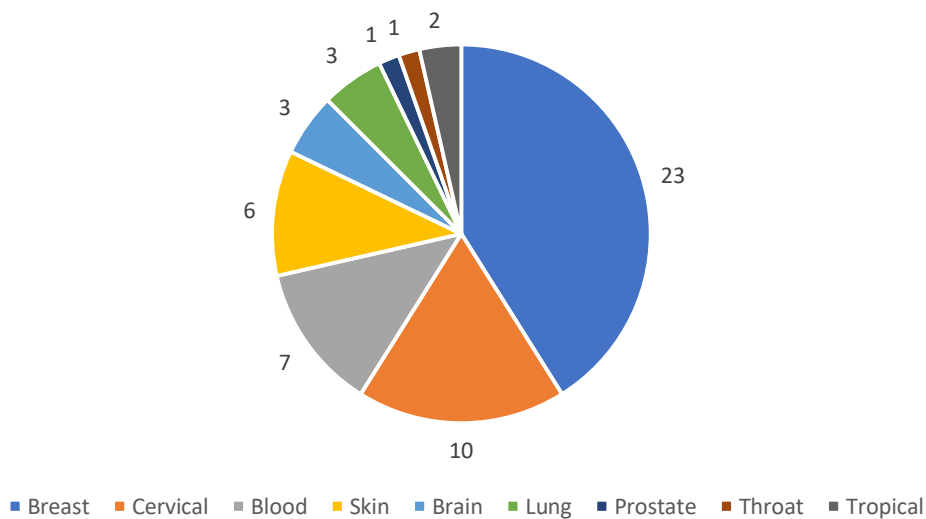
Of the 30 survey respondents, one participant stated they have had cancer. Seven participants (23%) stated they have a family member who has had cancer. Although cancer was not extremely prevalent among survey respondents, 73% of respondents (n=22) claimed cancer is a worry of theirs. Zero of the female respondents have had the HPV vaccine, and most of the focus group participants either asked what the vaccine is or mentioned that they have never heard of it. In focus groups, some believed cancer is a significant cause of death and is a problem, but many believed it is not a concern for the community since it is rare, showing conflicting perceptions of community members. When asked, most focus group participants claimed skin cancer is not a worry of theirs, or the community's.

When asked which three cancers are the greatest concern for the community, every participant who responded (n=23) answered breast cancer. Women were slightly more likely to say breast cancer is the most important, though it was not significant (p=0.060). When participants were asked which three cancers present the greatest problem in their community, the following responses were totaled and recorded:

TABLE 1: Respondents' perceived three most common types of cancer in the community

Type of Cancer	Number of Responses
Breast	23
Cervical	10
Blood	7
Skin	6
Brain	3
Lung	3
Tropical	2
Prostate	1
Throat	1

FIGURE 1: Respondents' perceived three most common types of cancer in the community

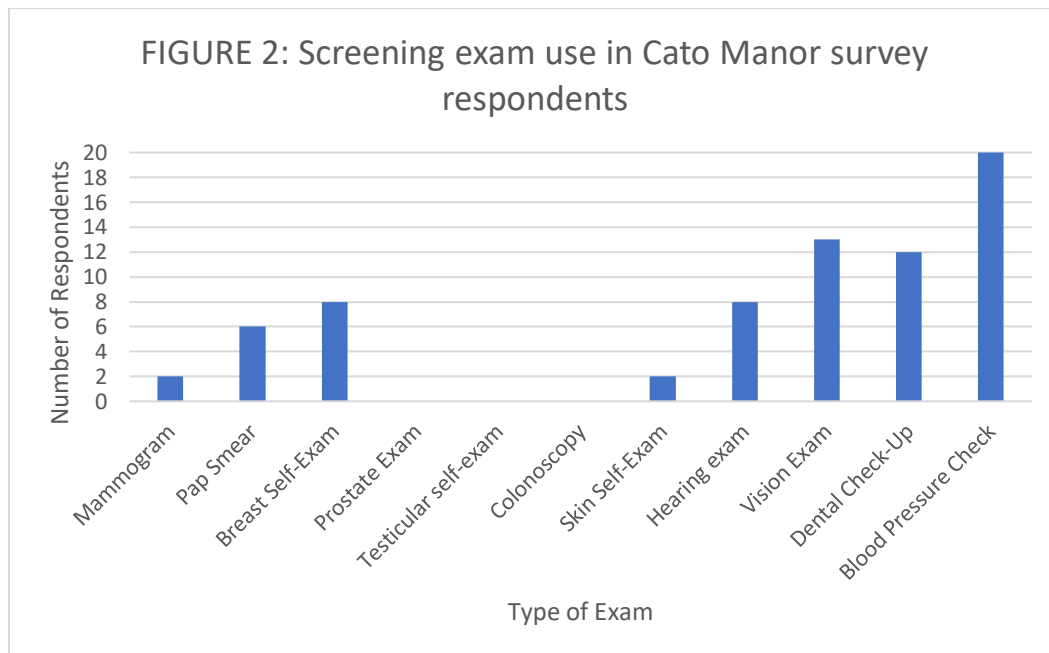


## Screening Findings

After asking survey respondents about their use of cancer screening exams, it was clear that most, if not all, were not being screened as often as the national health guidelines recommend. In the last 10 years, only 40% (n=6) of women have had a Pap smear. Only 13% (n=2) of women have ever had a mammogram. Roughly 53% (n=8) of women reported performing a self-breast exam in the last year. No one surveyed reported ever having a colonoscopy, and no men reported ever having a testicular or



prostate exam. Less than 7% (n=2) of respondents stated they have ever performed a self-skin exam. The most popular exam was a blood pressure exam (n=20). Seven respondents stated they have never had any of the 11 exams which can detect cancer or other health abnormalities included in the survey (mammogram, self-breast exam, Pap smear, prostate exam, colonoscopy, hearing exam, vision exam, self-testicular exam, dental check-up, self-skin exam, and blood pressure check).



Of the survey respondents, the average number of screening tests recorded was 2.36. Women received significantly more screening exams, at an average of 3.2 compared to the average among men of 1.5 ( $T=2.2$ ,  $p=0.044$ ). There was a positive relationship between age and getting screening exams, as well ( $R=.42$ ,  $p=0.020$ ). There was a relationship between knowing where to get screened and getting screening exams ( $R=.50$ ,  $p=.0045$ ). Survey respondents who had a better understanding of cancer risk factors were more likely to get screening exams ( $p=0.00046$ ).

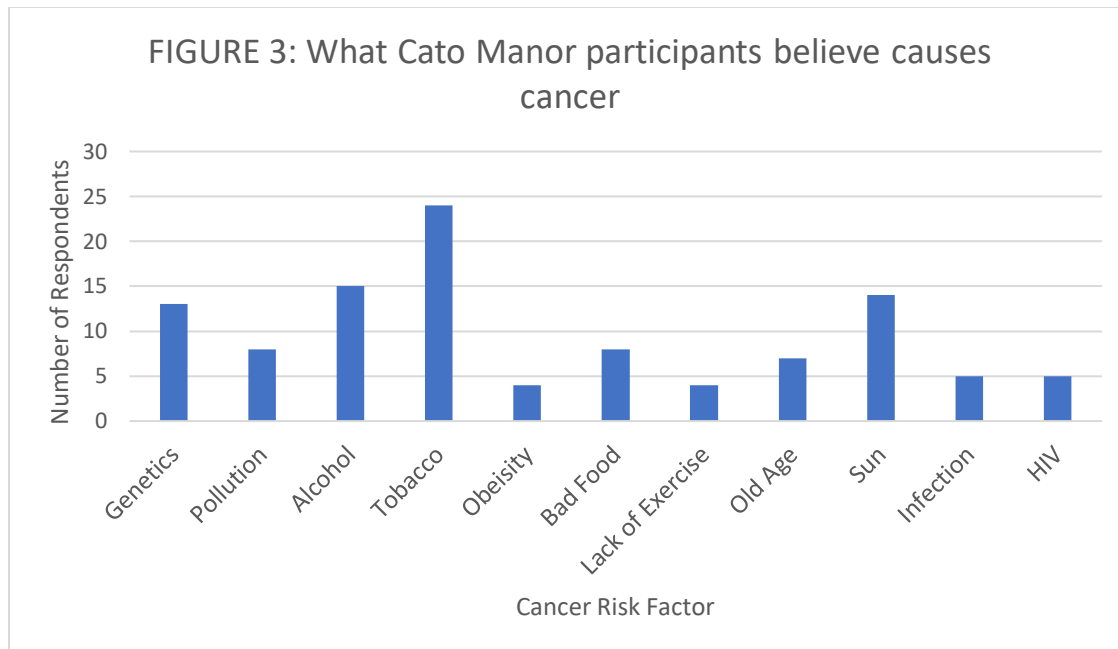
One gender was not more likely to state they worry about getting cancer. No statistically significant relationship between stating that a cancer is a worry of one's and

getting four or more screening exams was found ( $p=1.0$ ). Though not statistically significant, education was slightly associated with being less likely to worry about getting cancer ( $p=0.27$ ). Education was also slightly associated with being less likely to feel like one has the power to reduce their risk of getting cancer ( $p=0.52$ ).

There was no statistically significant relationship between having insurance or employment and feeling like one can afford screening exams. No statistically significant relationship was found between getting screening exams and education, employment status or insurance.

## Knowledge of Cancer Findings

Roughly 77% of respondents ( $n=23$ ) claimed they would like to learn more about cancer. Of those respondents, three claimed they would like to learn “everything” about cancer. No measured demographic information was significantly associated with increased knowledge of risk factors for cancer. There was no relationship between perceived understanding of cancer and education, age, or any other measured demographic factors. Women were slightly less likely to feel like they have a good understanding of cancer, though not statistically significant ( $p=0.58$ ).

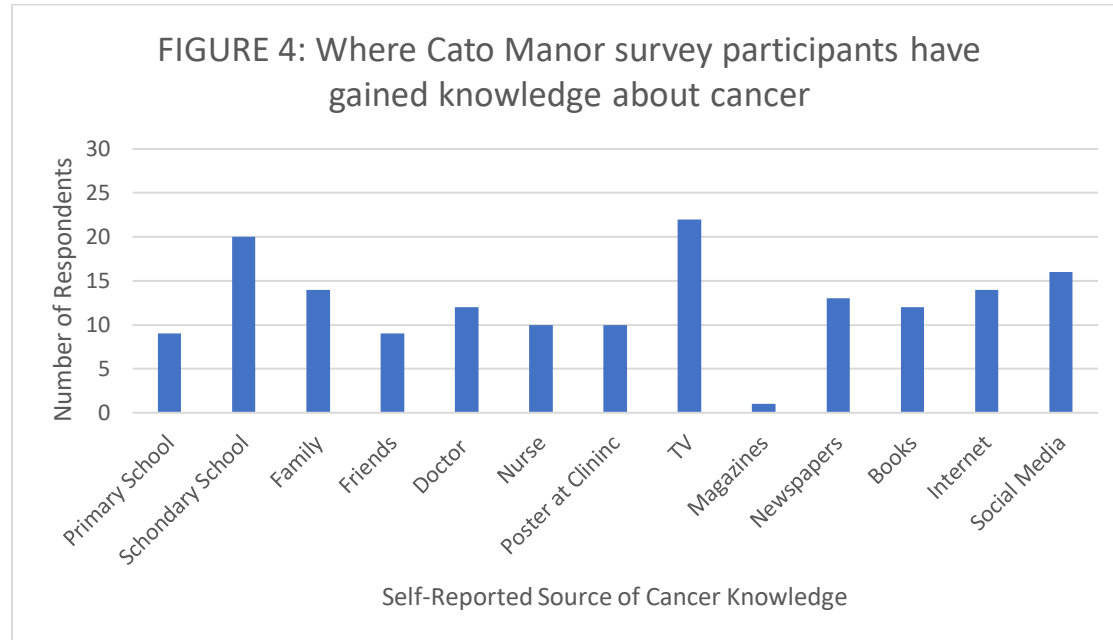


TV was the most popular place to learn about cancer, followed by secondary school, social media, the internet, then family. An estimated 68% of households in Cato Manor have TVs, suggesting that it is likely that a much larger percent of those who own a TV gain cancer knowledge from it (Municipal Elections, 2016). Only 40% of respondents who went to college or university ( $n=2$ ) stated they learned about cancer there. When asked in a focus group where they learned about cancer, participants first mentioned school, TV, social media, and the internet.

When participants were asked in a focus group where they learned about cancer, doctors and the clinic were an afterthought, only mentioned after moments of silence, along with cereal boxes. In a focus group discussion, participant #2 claimed "You only know that [there are cancer screening programs] if you go to the clinic" (pers. comm., 2018). Over 93% of survey respondents ( $n=28$ ) claimed they would feel comfortable talking to their doctor about cancer. Of the other two respondents, one stated they were unsure and one claimed they strongly disagreed. Women were slightly more likely to feel comfortable talking to their doctor about cancer, though it was not statistically

significant ( $p=0.096$ ). To express the relationship between clinics and cancer knowledge, participant #30 claimed:

*"The health is bad here, like the healthcare. We usually go to clinic, but I think they don't really tell us [about cancer]. I don't know a lot about cancer... You can go to the clinics to get information, but you don't have time for that" (pers. comm., 2018).*

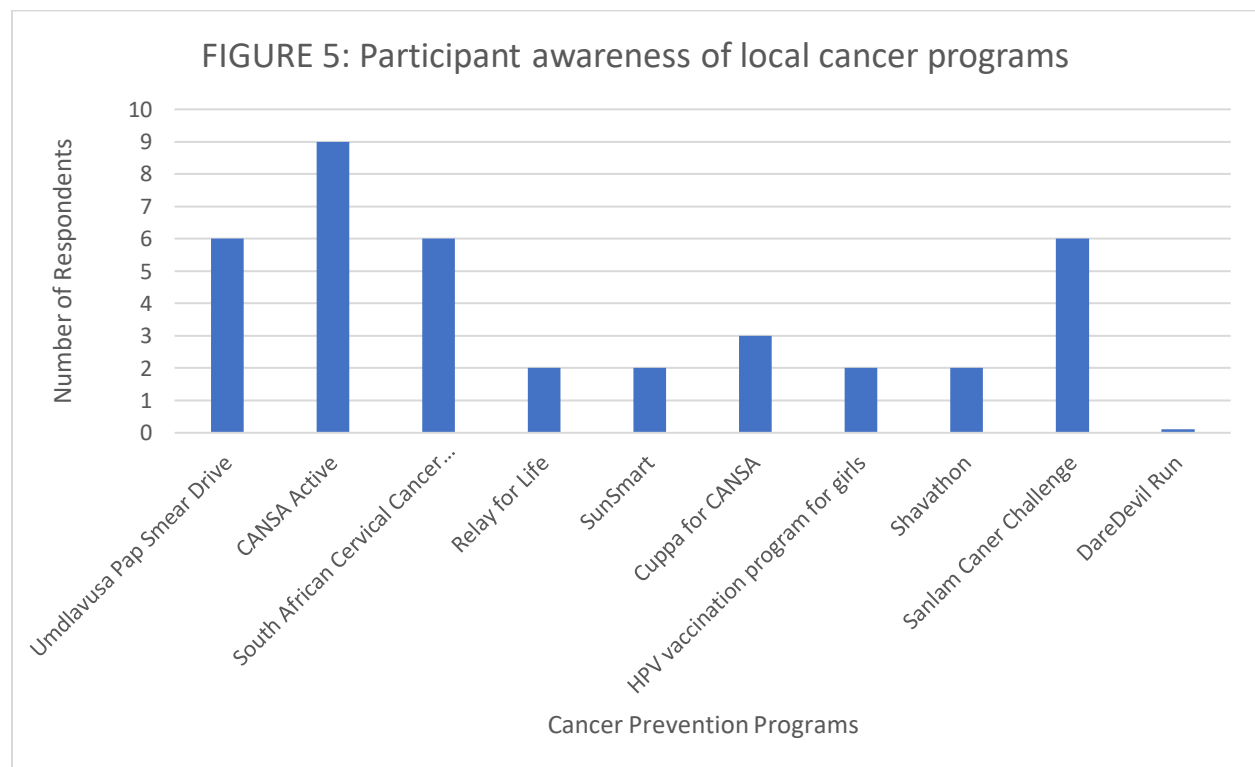


## Current Cancer Prevention Programs

Thirty percent of participants ( $n=9$ ) haven't heard of any of the 10 cancer screening and prevention programs in Durban which were included in the survey. When asked why that may be, participant #10 said, "I think they [cancer awareness programs] are only in Durban" (pers. comm., 2018). Participant #1 then said, "The majority of the people in the community haven't been educated about cancer. We don't get cancer awareness here" (pers. comm., 2018). When CANSA was mentioned in a focus group session, several participants expressed that they have heard of the organization, but still did not know of any CANSA-sponsored awareness programs in the area.

When asked if community members would use cancer screening and prevention programs if they were in the community, the participants overwhelmingly responded “yes.” However, participant #12 doubted this, due to the nature of cancer and the way he has seen people respond to illness in his lifetime. He claimed, “People only worry about sickness when it hits them” (pers. comm., 2018).

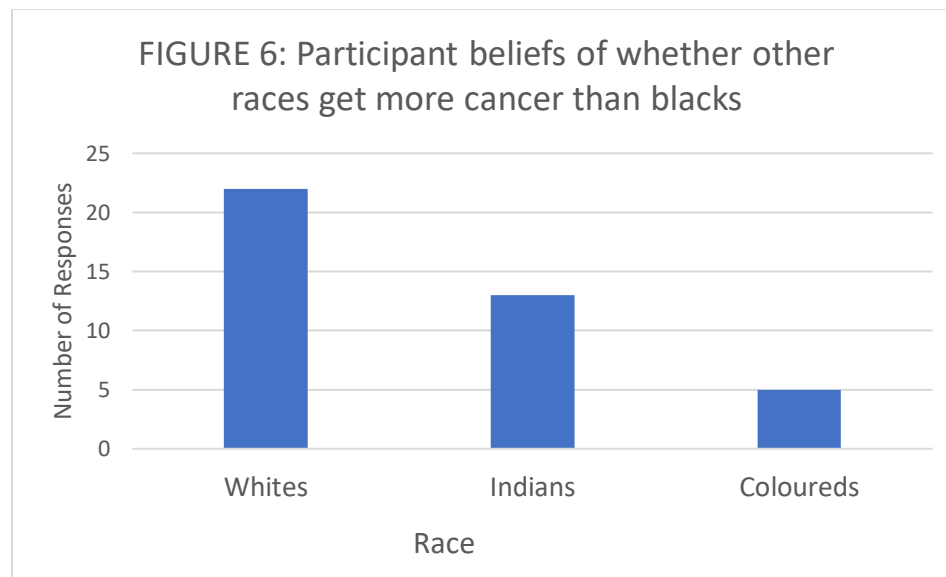
Women were more likely to have heard of cervical cancer programs, though not significant ( $R=.48$ ,  $p=.0067$ ). However, there was no association between age and having heard of cervical cancer programs or having a Pap smear and knowing about cervical cancer programs.



## Race

Concepts related to race appeared to significantly influence cancer-related health behavior. Seventy-three percent of survey respondents ( $n=22$ ) believed whites get more

cancer than blacks. Forty-three percent (n=13) believed Indians get more cancer and 17% (n=5) believed coloureds get more cancer than blacks. The cause of this perceived racial disparity in cancer incidence was debated. When asked why they believed this, participant #30 said it was because, "Most of the people in hospitals that had cancer were white" (pers. comm., 2018). Participant #12 claimed he's simply "never met a black person with cancer." He believed it could be because white people "smoke more than us" (pers. comm., 2018). Participant #8 claimed whites get more cancer because, "It's the pigmentation. It's the sun" (pers. comm., 2018). Participant #9 then claimed, "White people use sunscreen. Take albinos for instance. Their skin is weak, it's not strong. It gets infected by the sun easily" (pers. comm., 2018). This brought up the concept of a power dynamic based on the strength of one's skin, which is reflected through its pigmentation and color. Participant #8 then continued, "It's the color of the skin, it makes a difference because fair people get most diseases" (pers. comm., 2018).



There are also historical trends which may have impacted how most participants believed blacks do not get as much cancer as whites. Participant #12 claimed, "Black people get HIV and white people get cancer" (pers. comm., 2018). In the focus groups, it

became clear that this belief was once held by many. However, now many people are realizing that cancer does in fact affect black South Africans. Participant #30 said, "It never hit us... We just thought HIV was just for us [black people] because not a lot of white people get HIV. We were like, okay, well, I guess cancer is for them and HIV is for us" (pers. comm., 2018).

This respondent then considered why black people so suddenly started getting cancer, when many believed they could not get the disease at one point. She said, "They used to go and make gardens and be active... healthy. Everything they ate was organic. They'd grow their own food... I think it's because we adapted so much into whites' lifestyle. I remember my granny saying how she doesn't want any food from America... My granny is 96 and she has no diseases beside diabetes. She's like, 'To see my daughters die from cancer and I've never had that disease and here I am, old as I am.' She's like, 'It's because you guys are so modernized'" (pers. comm., 2018). This brought up the belief that white culture is what has caused black South Africans to get cancer when they hadn't originally been affected by the disease.

## HIV

There was a relationship between having HIV and knowing that women who are HIV positive should be checked for cervical cancer more often than women who are not HIV positive ( $p=.030$ ). However, people who stated they have HIV were slightly, though not statistically significant, less likely to know HIV can cause cancer ( $p=.38$ ). It is important to note only 10% of the already small group of survey participants ( $n=3$ ) disclosed they are HIV positive, and therefore, the accuracy of the conclusions drawn with regard to trends in these data may not be as accurate as others. In an interview, Participant #30 brought up the idea that the high prevalence of HIV among black South Africans may cause their cancer to be disregarded or misdiagnosed as HIV. She said,

"My dad's aunt passed away from cancer. She didn't know. A lot of people thought she was dying of HIV because she kept getting skinnier and skinnier" (pers. comm., 2018).

## Fear of the Unknown and Ineffective Treatment

When discussing reasons why so many people rarely get screened for cancer, a common idea which continued to arise in focus groups was fear. Participant #12 claimed, "If you seek [screening exams], you know you'll find [cancer] and if you find that you have cancer, why do you seek?" He later said, "[With cancer], you will die" (pers. comm., 2018). In another focus group, one participant claimed he would rather have HIV than cancer. He believed, "HIV you can treat. Cancer is a death sentence" (pers. comm., 2018). This shows the poor availability of effective treatment causes some to believe cancer is a death sentence. They claimed it is better for one to live a happy life without knowing they are dying than to learn one has cancer and not be able to do nothing. Participant #2 added, "Some of us are scared of the answer, so we wouldn't just go throw ourselves in the deep end with stigma of cancer. You can go get tested and figure out you have cancer and die, so might as well don't know for some people" (pers. comm., 2018). Participant #12 then added, "You don't suffer from what you don't know" (pers. comm., 2018). Poor options when it comes to treatment also appears to act as a barrier for getting screened and diagnosed. Focus group participants told stories of family members who went through chemotherapy, not mentioning anyone who survived it. One participant believed, "Chemo is the one that kills the most, so might as well don't get it" (pers. comm., 2018).

However, some disagreed, explaining that they believe it is better to get diagnosed and try to fight the disease. Participant #13 explained, "You get to know more about the disease. Some people might find out they have it and might be oblivious. At least you prolong yourself when you're going in for chemo" (pers. comm.,



2018). Participant #12 then added, "Having cancer doesn't mean you're going to die. There are ways you might survive." Finally, when asked why they think some people with the resources don't get screened, participant #12 explained that he has other worries which are more important. "Humans kill. I think I'm going to die by humans. Humans will kill me. Not cancer. Humans" (pers. comm., 2018).

## ANALYSIS

### Barriers to Cancer Screening

Possibly due to the sample size, factors which have been shown to influence getting screening exams in literature including education, employment, age, medical aid, private health insurance, chronic medical conditions were not shown to be associated with a significant increase in screening exam use. However, through interviews and focus group discussions, some other barriers which have been shown to influence cancer screening such as trust in the medical system, fear of being diagnosed, and stigma were shown to be barriers. This shows that it is important to prioritize reducing these barriers, since they are clearly prevalent in the community members of Cato Manor who participated in this study and could therefore make an impact.

### Cancer Findings

#### *HPV and Cervical Cancer*

One of the most surprising findings was that zero of the 30 survey respondents have had the HPV vaccine, and very few even knew what it is. Although the HPV vaccine is still a relatively new vaccine, the Medicines Control Council of South Africa approved its use over 10 years ago. Over 73% (n=11) of female survey respondents would have been in their teenage years 10 years ago, and therefore would have had the vaccine if it was fully accessible. This shows it is very possible that there are still disparities in access to vaccines such as HPV. Although theoretically there should not still be disparities since the HPV vaccine is now given out in public schools, the fact that so many respondents have never even heard of the vaccine or virus would suggest otherwise. Additionally, since there was no significant association between having heard of cervical cancer awareness programs and having a Pap smear, it is still difficult to know whether

awareness programs are causing people to get screened and actually improve cancer prognoses.

### *Prostate and Colorectal Cancers*

In 2014, prostate cancer was the most common cancer among South African men. Zero of the 15 men surveyed stated they have ever had a prostate or testicular exam, suggesting there is great room for improvement and it is an area which programs should address. When asked what the three most common types of cancer are in the community, prostate cancer was only mentioned once. This could be due to the possible low prevalence of prostate cancer, or more likely, the lack of awareness. None of the survey respondents stated they have even heard of the DareDevil Run in Durban which works to increase awareness of prostate cancer. This shows current awareness programs aren't reaching townships like Cato Manor. Similarly, zero of the 30 respondents stated they have ever had a colonoscopy. Colorectal cancer is the second most common type of cancer in men and the fourth most common in women in South Africa. Additionally, many participants asked what a colonoscopy is, since they have never heard of the exam. This shows that awareness programs should work to increase knowledge of and access to screening for colorectal cancers in the community, as well.

### *Blood and Skin Cancers*

Only 6.7% of participants (n=2) stated they have heard of SunSmart, a CANSA program which works to increase awareness of skin cancer. This shows not only that another cancer awareness program is not reaching townships like Cato Manor, but also that the community is getting its knowledge of skin cancer elsewhere. When participants were asked what the three most common types of cancer are in their community, skin cancer was the fourth most common answer (n=6). This shows that participants believe

skin cancer is a problem, yet it appears government programs are not addressing it.

Kaposi's sarcoma, which causes skin lesions, is the fifth most common type of cancer among men in South Africa. Only two participants claimed they have ever performed a self-skin exam, presenting a health concern, since skin cancers are common.

When asked what the three most common types of cancer in the community are, seven people answered blood cancer. However, 71% of these respondents (n=5) were female and lived on the same street in Cato Manor. Since one participant mentioned a neighbor had blood cancer, I speculate a possible source of error which has caused people to believe blood cancer is more common than it actually is.

## Suggestions for Current Cancer Programs

### *Move Cancer Awareness Programs into Townships*

One barrier which was identified is the fact that so few participants have heard of CANSA awareness programs, causing them to lack access to knowledge which others may have. When asked about these programs, multiple focus group participants stated simply that the programs only operate in Durban. Therefore, cancer screening and prevention programs must immediately move into townships outside of Durban such as Cato Manor and Chesterville in order to make the greatest impact and reduce geographic health disparities.

### *Improve Prognosis and Reduce Fear of Cancer*

It was clear that many avoid cancer screening and diagnostic tests because they fear the result. Due to ineffective and inaccessible treatment, many consider cancer to be a death sentence. Some stated even if they could get treatment, it rarely works, so why bother? Therefore, it is necessary to improve cancer prognoses in order for people

to not fear being tested for cancer. If they no longer fear screening tests, people will be more likely to be screened often and catch cancer earlier when the prognosis is better.

### *Target Programs*

This study found several areas of lacking knowledge which must be addressed, such as prostate and colorectal cancer and screening for those cancers. It was also demonstrated that certain sources of education, such as secondary school, TV, and social media, have possibly had an impact. Data showed that educational attainment and age aren't necessarily correlated with increased knowledge of cancer. Therefore, the entire population must be targeted to increase cancer knowledge. This study showed TV is probably the most effective way to teach community members of Cato Manor about cancer, so TV programs should continue. It also showed that most (75%) of the people who gained knowledge about cancer on social media also did so on the internet. Therefore, since it is most of the same audience, it would be most effective to target either social media or internet users and focus other campaigns on other groups. Finally, it is important to insure the HPV vaccination program in public schools is fully implemented, especially in communities such as Cato Manor, since many survey respondents still have not heard of the vaccine.

### *Address Racial Disparities*

Most of the survey respondents believe cancer is a "white disease," affecting more whites than blacks. However, current cancer research shows otherwise, that blacks are at greater risk of getting cancer than any other racial group in South Africa. Campaigns must work to educate black South Africans, so they know it is possible to get cancer and that they must be aware of it. It is important for healthcare providers to not

assume a black person who has been feeling unwell has HIV, as seen in participant #30 who claimed everyone assumed her great aunt had HIV when she then died of cancer.

## *Educate*

Education can allow one to feel empowered, encouraging them to get screened for cancer. It is clear from survey responses that participants want to learn more about cancer. They want to protect themselves, and interviews made it clear people are willing to dramatically change their actions to avoid cancer. It is also clear there are gaps in cancer knowledge which should be addressed. Data showed people who know where to get screened are more likely to get screening exams. Although it is possible that the participants know where to get screened because they have already had exams, it is also possible that people are more likely to get exams simply because they know where to go. Therefore, it is important to ensure that everyone knows where to get screened, and they are able to get there.

The data suggested people with HIV were more likely to know HIV positive people must be checked for cervical cancer more often, suggesting counseling of people after HIV diagnosis is probably occurring. However, the participants with HIV were also slightly less likely to know HIV can causes cancer, suggesting there is more they need to know about their own health.

While discussing cancer with focus group participants and interviewees, it became clear there are many misconceptions about cancer which should be addressed in order to help community members be as educated as possible. Several participants, both in surveys and discussions described cervical cancer as "cancer of the womb." Two survey respondents mentioned that "tropical cancer" is a big problem in their community, and one survey respondent believed smoking marijuana can cause cancer. It remains unknown to what exactly "tropical cancer" was referring. While those misconceptions aren't necessarily dangerous, they show areas where the community

should be educated more. Participant #30 claimed, "Some people believe we can't get infected because of our blood type." This could potentially lead to people partaking in what they know is risky behavior, such as smoking, since they believe their blood can protect them from cancer. She then claimed, "My aunt has this thing, [she believes] cooking food in a microwave causes cancer. And now we are all scared to use a microwave. We use a pot now. You know how much work that is?" (pers. comm., 2018). This shows people will go through great lengths to protect themselves and their family members from cancer, but they can lack the knowledge to make the most of that effort.

## CONCLUSION

Despite medical and technological advances, cancer continues to be a significant problem for public health across the globe. To address this problem, numerous programs which aim to reduce the burden of cancer through increasing screening and awareness have been created in South Africa. However, it is difficult to measure the impact of these programs without assessing the knowledge regarding cancer which communities possess. This study aimed to identify current knowledge about cancer and screening processes, and in doing so, shed light on the effectiveness of screening and prevention programs on the residents of Cato Manor.

This study found the greatest gaps in knowledge are around prostate and colorectal cancer, and the belief that blacks can't get cancer. It also found women were more likely to get screening exams. Age and knowing where to get screening exams were positively associated with having the exams. Finally, participants who had a better understanding of cancer risk factors were more likely to get screening exams. This study also identified major barriers to receiving cancer screening exams, such as fear of diagnosis due to poor prognosis and treatment options.

This study hoped to gauge whether current cancer screening and prevention programs in the community are effective. It found that in general, cancer screening programs were not well-known or utilized. Even when participants had heard of various cancer awareness programs, it oftentimes did not affect their knowledge of cancer or their behavior. This shows that current cancer awareness programs are not accessible or making a visible significant impact on the community. It is clear that survey respondents wanted to know more about cancer and most claimed it is a worry of theirs. Participants wanted to reduce their chances of getting the disease, but barriers, such as lack of education and ineffective treatment options continue to stand in the way of that.



## RECOMMENDATIONS for FUTURE STUDY

Due to time constraints, the survey was administered to only 30 residents of Cato Manor. It would be beneficial to repeat this study with a larger sample size to increase the reliability of data and reduce bias. It would also be informative to repeat the study in a couple years to see if anything has changed.

Although it was out of the scope of this project, preliminary finding suggested it is common knowledge that smoking significantly increases one's risk of getting cancer. However, smoking remains a common practice in the community. It would be interesting to learn more about the relationship between knowledge and behavior to see whether health education programs actually dramatically reduce unhealthy behaviors such as smoking.

It would be interesting to assess in further studies the effectiveness of current cancer screening and prevention programs, since this study simply looked at whether participants have heard of the programs. It would also be beneficial to investigate the community's knowledge of the relationship between HIV and cancer, since only 20% of participants stated they knew HIV causes cancer and only 33% claimed they knew women with HIV should be checked for cervical more often than women without HIV. Finally, during focus group discussion, multiple people claimed black South Africans cannot get skin cancer. More research should be done to see how common that belief is and whether that harms health and influences behavior.

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## APPENDICES

### *Appendix 1: Glossary of Medical Terminology*

HPV – Short for human papillomavirus, this viral infection can be spread through skin-to-skin contact but is also the most common sexually transmitted infection that affects both men and women. It has been shown to increase a woman's risk of cervical cancer.

HPV vaccine – The HPV vaccine can prevent against the types of HPV which are associated with cancer. The CDC recommends the vaccine for boys and girls ages 11 to 12, but the vaccine is still effective at later ages. However, the vaccine is only effective when administered as prophylaxis, before exposure.

Mammogram – Mammograms use X-rays to check for abnormalities in breast tissue. They are used to screen and detect breast cancer early. Mammograms are recommended yearly for women of high risk in South Africa and are not discouraged for women of moderate risk. The American Cancer Society recommends yearly mammograms for women between the ages of 45 to 54.

Pap smear – A Pap smear is a test which collects cells from the cervix. They are most often used to detect cervical cancer. Pap smears are recommended for women over the age of 30 in South Africa every 10 years. Pap smears are recommended for women who are HIV positive every three years, since they are at higher risk for cervical cancer.

Skin self-exam – A skin self-exam is an exam during which one checks their skin for any changes to detect skin cancer as early as possible.

Colonoscopy – During a colonoscopy, doctors perform an endoscopic exam to examine the large intestine. Colonoscopies are recommended to screen for colorectal cancer starting at age 50.

## Appendices

### *Appendix 2: Cancer Screening and Prevention Survey*

\*If you are uncomfortable discussing personal experiences with cancer, please skip questions 11-13. If you believe the focus group discussion about cancer later on may be upsetting for any reason, you can leave at any point and are not required to participate.

1. What is your age? \_\_\_\_\_
2. What is your gender? \_\_\_\_\_
3. Where do you currently live? \_\_\_\_\_
4. Where did you go to primary school? \_\_\_\_\_
5. Where did you go to secondary school? \_\_\_\_\_
6. What is the highest level of education you have achieved?
  - ☐ Grade 11
  - ☐ Grade 12
  - ☐ Certificate
  - ☐ Diploma/college/undergraduate
  - ☐ Degree
7. Are you currently a student?
  - ☐ Yes
  - ☐ No
8. What is your current employment status?
  - ☐ Full-time
  - ☐ Part-time
  - ☐ Not employed
9. Do you have a chronic medical condition?
  - ☐ Yes If yes, please specify \_\_\_\_\_
  - ☐ No
10. What type of health or medical insurance do you have?
  - ☐ State/government

- ☐ Private  
☐ None

11. Have you ever had cancer?

- ☐ Yes If yes, what type of cancer? \_\_\_\_\_  
☐ No

12. Has anyone in your family had cancer?

- ☐ Yes If yes, who and what type of cancer?  
 \_\_\_\_\_  
 \_\_\_\_\_

- ☐ No  
☐ Unsure

How strongly do you agree with the following statements? Put a tick "✓" on the option you most agree with.

	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
13. I worry about getting cancer.					
14. I would feel comfortable talking to my doctor about cancer.					
15. I think I have a good understanding of cancer					
16. I know where to get screened for cancer.					
17. I can afford to get screened for cancer.					
18. I feel like I have the power to decrease my risk of getting cancer.					

19. Have you received the HPV vaccine?

- ☐ Yes

- ☐ No
- ☐ Unsure

20. Do you know that women who are HIV positive should get tested for cervical cancer more often than women who do not have HIV?

- ☐ Yes
- ☐ No
- ☐ Unsure

21. Where have you gained knowledge about cancer? Tick "✓" all that apply.

- ☐ Primary school
- ☐ Secondary school
- ☐ University or college
- ☐ Family
- ☐ Friends
- ☐ Doctor at a clinic
- ☐ Nurse at a clinic
- ☐ Papers or posters at the clinic
- ☐ TV or movies
- ☐ Magazines
- ☐ Newspapers
- ☐ Books
- ☐ Internet
- ☐ Social media
- ☐ Other, please specify \_\_\_\_\_

22. Where have you learned the most about cancer? Please list the most important source of information as number 1, the second most important as number 2 and the third most important as number 3.

- 1.
- 2.
- 3.

23. What do you think are the three most common types of cancer in your community?

1. \_\_\_\_\_  
\_\_\_\_\_
2. \_\_\_\_\_  
\_\_\_\_\_

3. \_\_\_\_\_  
\_\_\_\_\_

24. Have you had any of the following exams? Tick "✓" all that apply.

- |  |                             |
|--|-----------------------------|
| <input type="checkbox"/> Mammogram                   | If yes, how long ago? _____ |
| <input type="checkbox"/> Breast self-exam            | If yes, how long ago? _____ |
| <input type="checkbox"/> Pap smear                   | If yes, how long ago? _____ |
| <input type="checkbox"/> Prostate exam               | If yes, how long ago? _____ |
| <input type="checkbox"/> Colonoscopy                 | If yes, how long ago? _____ |
| <input type="checkbox"/> Hearing exam                | If yes, how long ago? _____ |
| <input type="checkbox"/> Eye exam                    | If yes, how long ago? _____ |
| <input type="checkbox"/> Skin self-exam              | If yes, how long ago? _____ |
| <input type="checkbox"/> Testicular self-exam        | If yes, how long ago? _____ |
| <input type="checkbox"/> Dental check-up             | If yes, how long ago? _____ |
| <input type="checkbox"/> Blood pressure check        | If yes, how long ago? _____ |
| <input type="checkbox"/> Other, please specify _____ |                             |

25. Which of the following do you think causes cancer? Tick "✓" all that apply.

- ☐ Genetics
- ☐ Pollution
- ☐ Alcohol
- ☐ Cigarette smoke/ tobacco
- ☐ Obesity
- ☐ Eating bad food
- ☐ Not exercising regularly
- ☐ Old age
- ☐ Sun exposure
- ☐ Infection
- ☐ HIV
- ☐ Using dagga/marijuana

26. What do you think are the two most important things a person can do to decrease their risk of getting cancer?

1. \_\_\_\_\_  
\_\_\_\_\_

2. \_\_\_\_\_  
\_\_\_\_\_

27. Do you think other races get more cancer than black people? Tick "✓" all that apply.

- ☐ Whites
- ☐ Indians
- ☐ Coloureds
- ☐ Other, please specify \_\_\_\_\_

28. Which programs have you heard of in your community?

- ☐ Umdlavusa Pap Smear Drive
- ☐ Relay for Life
- ☐ South African Cervical Cancer Screening Program
- ☐ HPV vaccination program for girls
- ☐ SunSmart
- ☐ Shavathon
- ☐ Hollard DareDevil Run
- ☐ Cuppa for CANSA
- ☐ Sanlam Cancer Challenge
- ☐ CANSA Active

29. What more would you like to learn about cancer?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Appendices

### *Appendix 3: Demographic Information of Survey Respondents*

Residents of Cato Manor are 97% black African and 82% Zulu-speaking (Municipal Elections, 2016). All 30 respondents were black South African and Zulu-speaking residents of the townships Cato Manor or Chesterville, KwaZulu-Natal. Roughly 83% (n=25) of respondents currently reside in Cato Manor. The other respondents reside in Chesterville. The mean age of survey participants was 29.3 and the median age was 25.5.

Survey participants were 50% male (n=15) and 50% female (n=15). Nearly 27% (n=8) of participants are currently students. About 16% (n=5) claimed they have a chronic medical condition.

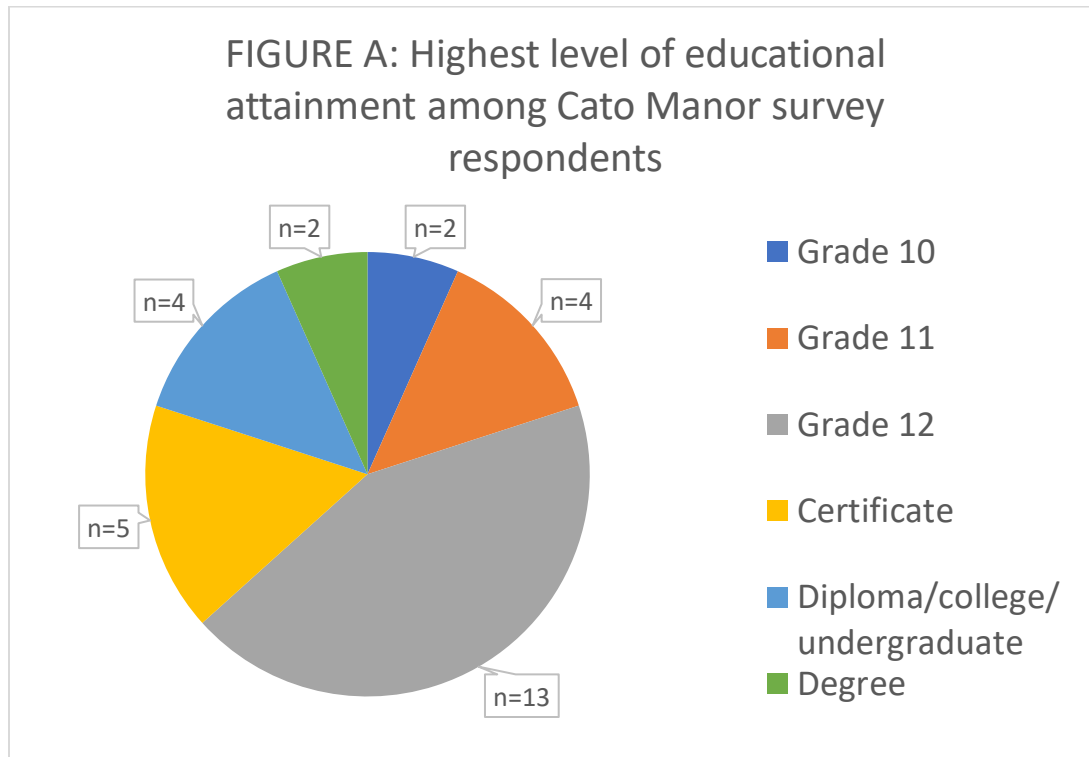




FIGURE B: Employment status among Cato Manor survey respondents

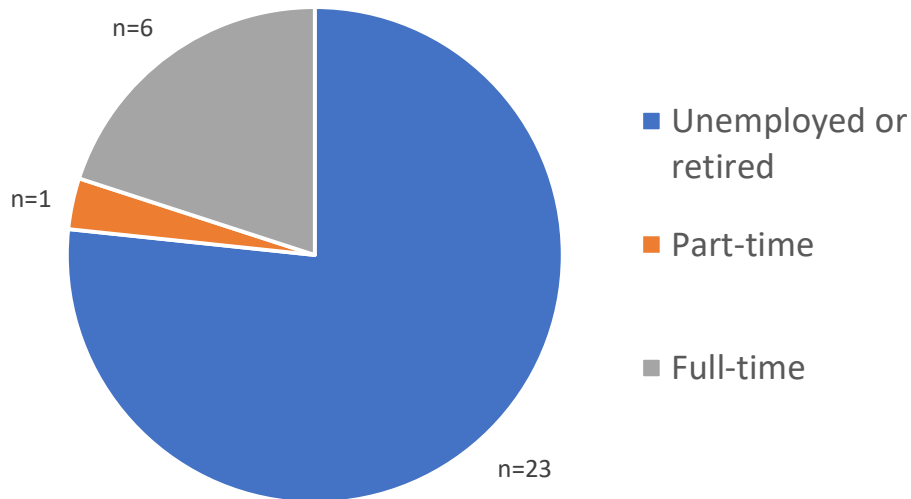
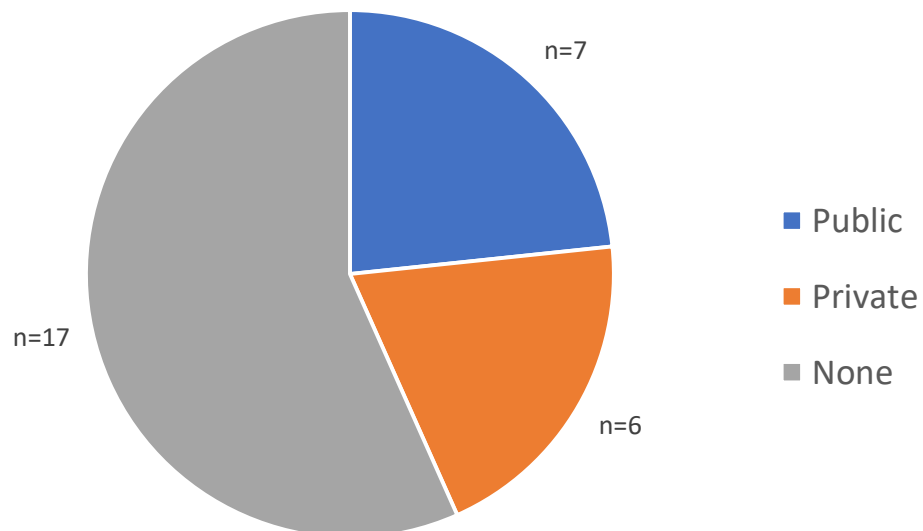


FIGURE C: Type of medical insurance coverage among Cato Manor survey respondents



## Appendices

### *Appendix 4: Statement of Ethics Form*

(Adapted from the American Anthropological Association)

This document must be read, signed, and submitted to the AD prior to ethics review meeting.

In the course of field study, complex relationships, misunderstandings, conflicts, and the need to make choices among apparently incompatible values are constantly generated. The fundamental responsibility of students is to anticipate such difficulties to the best of their ability and to resolve them in ways that are compatible with the principles stated here. If a student feels such resolution is impossible, or is unsure how to proceed, s/he should consult as immediately as possible with the Project Advisor and/or AD and discontinue the field study until some resolution has been achieved. Failure to consult in cases which, in the opinion of the AD and Project Advisor, could clearly have been anticipated, can result in disciplinary action as delineated in the “failure to comply” section of this document. Students must respect, protect, and promote the rights and the welfare of all those affected by their work. The following general principles and guidelines are fundamental to ethical field study:

#### **I. Responsibility to people whose lives and cultures are studied**

Students' first responsibility is to those whose lives and cultures they study. Should conflicts of interest arise, the interests of these people take precedence over other considerations, including the success of the Independent Study Project (ISP) itself, for if the ISP has negative repercussions for any members of the target culture, the project can hardly be called a success. Students must do everything in their power to protect the dignity and privacy of the people with whom they conduct field study.

The rights, interests, safety, and sensitivities of those who entrust information to students must be safeguarded. The right of those providing information to students either to remain anonymous or to receive recognition is to be respected and defended. It is the responsibility of students to make every effort to determine the preferences of those providing information and to comply with their wishes. It should be made clear to anyone providing information that despite the students' best intentions and efforts anonymity may be compromised or recognition fail to materialize. Students should not reveal the identity of groups or persons whose anonymity is protected through the use of pseudonyms.

Students must be candid from the outset in the communities where they work that they are students. The aims of their Independent Study Projects should be clearly communicated to those among whom they work.

Students must acknowledge the help and services they receive. They must recognize their obligation to reciprocate in appropriate ways.

To the best of their ability, students have an obligation to assess both the positive and negative consequences of their field study. They should inform individuals and groups likely to be affected of any possible consequences relevant to them that they anticipate.

Students must take into account and, where relevant and to the best of their ability, make explicit the extent to which their own personal and cultural values affect their field study.

Students must not represent as their own work, either in speaking or writing, materials or ideas directly taken from other sources. They must give full credit in speaking or writing to all those who have contributed to their work.

#### **II. Responsibilities to Hosts**

Students should be honest and candid in all dealings with their own institutions and with host institutions. They should ascertain that they will not be required to compromise either their responsibilities or ethics as a condition of permission to engage in field study. They will return a copy of their study to the institution sponsoring them and to the community that hosted them at the discretion of the institution(s) and/or community involved.

#### **III. Failure to comply**

When the AD(s) feel that the student has violated this statement of ethics, the student will be placed on probation. In the case of egregious violations, students can be subject to immediate dismissal under the conditions of the SIT STUDY ABROAD dismissal guidelines.

I, Lilly Hennessey, have read the above Statement of Ethics and agree to make every effort to comply with its provisions.

Date: 10-11-18

## Appendices

### *Appendix 5: Application for Review of Research with Human Subjects*



#### Human Subjects Review LRB/IRB ACTION FORM

Name of Student: <u>Lilly Hennessey</u>  ISP/Internship Title: <u>Knowledge regarding cancer screening and prevention in Cape Manor</u> Date Submitted: <u>12 October 2018</u>  Program: <u>SFH Durban Community Health</u>  Type of review:  Exempt <input type="checkbox"/> Expedited <input checked="" type="checkbox"/> Full <input type="checkbox"/>	Institution: <u>World Learning Inc.</u> IRB organization number: <u>IORG0004408</u> IRB registration number: <u>IRB00005219</u> Expires: <u>5 January 2021</u>  LRB members (print names): <u>John McGladdery</u> <u>Clive Bruzas</u> <u>Robin Joubert</u>  <b>LRB REVIEW BOARD ACTION:</b> <input checked="" type="checkbox"/> Approved as submitted <input type="checkbox"/> Approved pending changes <input type="checkbox"/> Requires full IRB review in Vermont <input type="checkbox"/> Disapproved  LRB Chair Signature: <u>[Signature]</u>  Date: <u>22 October 2018</u>
--	--

#### Form below for IRB Vermont use only:

#### Research requiring full IRB review. ACTION TAKEN:

☐ approved as submitted ☐ approved pending submission or revisions ☐ disapproved

IRB Chairperson's Signature

Date



## Appendices

### *Appendix 6: Adult Respondent Consent Form*

# SIT Study Abroad

a program of World Learning



## CONSENT FORM

### 1. Brief description of the purpose of this project

The purpose of this project is to understand the knowledge and practices regarding cancer screening and prevention. I hope to learn about what people know about cancer, including what causes it and whether it is a concern for the community. I am focusing on cancer screening, looking at whether people use screening tests and why that may be. I also would like to learn about what cancer prevention programs work in the community and whether they are effective.

### 2. Rights Notice

In an endeavor to uphold the ethical standards of all SIT ISP proposals, this study has been reviewed and approved by a Local Review Board or SIT Institutional Review Board. If at any time, you feel that you are at risk or exposed to unreasonable harm, you may terminate and stop the interview. Please take some time to carefully read the statements provided below.

- a. **Privacy** - all information you present in this interview may be recorded and safeguarded. If you do not want the information recorded, you need to let the interviewer know.
- b. **Anonymity** - all names in this study will be kept anonymous unless you choose otherwise.
- c. **Confidentiality** - all names will remain completely confidential and fully protected by the interviewer. By signing below, you give the interviewer full responsibility to uphold this contract and its contents. The interviewer will also sign a copy of this contract and give it to you.

I understand that I will receive **no gift** or direct benefit for participating in the study.

I understand that audio recordings of group discussions and interviews will be taken.

I confirm that the learner has given me the address of the nearest School for International Training Study Abroad Office should I wish to go there for information. (404 Cowey Park, Cowey Rd, Durban).

I know that if I have any questions or complaints about this study that I can contact anonymously, if I wish, the Director/s of the SIT South Africa Community Health Program (Zed McGladdery 0846834982 )

Participant's name printed

Lilly Hennessey

Interviewer's name printed

Your signature and date

*Lilly Hennessey* 10-12-18

Interviewer's signature and date

I can read English. If the participant cannot read, the onus is on the project author to ensure that the quality of consent is nonetheless without reproach.

## Appendices

### *Appendix 7: Consent to Use of ISP*

#### **Consent to Use of Independent Study Project (ISP)**

**SIT Study Abroad**

School for International Training



#### *Access, Use, and Publication of ISP/FSP*

Student Name: Lilly Hennessey

---

Email Address: lillyhennessey@gmail.com

---

Title of ISP/FSP: "If you seek, you know you will find and if you find you have cancer, why do you seek?" Knowledge and Practices Regarding Cancer Screening and Prevention in Cato Manor

---

Program and Term/Year: Fall 2018

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Student research (Independent Study Project, Field Study Project) is a product of field work and as such students have an obligation to assess both the positive and negative consequences of their field study. Ethical field work, as stipulated in the SIT Policy on Ethics, results in products that are shared with local and academic communities; therefore copies of ISP/FSPs are returned to the sponsoring institutions and the host communities, at the discretion of the institution(s) and/or community involved.

By signing this form, I certify my understanding that:

1. I retain ALL ownership rights of my ISP/FSP project and that I retain the right to use all, or part, of my project in future works.
2. World Learning/SIT Study Abroad may publish the ISP/FSP in the SIT Digital Collections, housed on World Learning's public website.
3. World Learning/SIT Study Abroad may archive, copy, or convert the ISP/FSP for non-commercial use, for preservation purposes, and to ensure future accessibility.
  - World Learning/SIT Study Abroad archives my ISP/FSP in the permanent collection at the SIT Study Abroad local country program office and/or at any World Learning office.
  - In some cases, partner institutions, organizations, or libraries in the host country house a copy of the ISP/FSP in their own national, regional, or local collections for enrichment and use of host country nationals.
4. World Learning/SIT Study Abroad has a non-exclusive, perpetual right to store and make available, including electronic online open access, to the ISP/FSP.
5. World Learning/SIT Study Abroad websites and SIT Digital Collections are publicly available via the Internet.

6. World Learning/SIT Study Abroad is not responsible for any unauthorized use of the ISP/FSP by any third party who might access it on the Internet or otherwise.
7. I have sought copyright permission for previously copyrighted content that is included in this ISP/FSP allowing distribution as specified above.



---

Student Signature

November 15, 2018

Date

**Withdrawal of Access, Use, and Publication of ISP/FSP**

Given your agreement to abide by the SIT Policy on Ethics, withdrawing permission for publication may constitute an infringement; the Academic Director will review to ensure ethical compliance.

☐

I hereby withdraw permission for World Learning/SIT Study Abroad to include my ISP/FSP in the Program's office permanent collection.

Reason:

☐

I hereby withdraw permission for World Learning/SIT Study Abroad to release my ISP/FSP in any format to individuals, organizations, or libraries in the host country for educational purposes as determined by World Learning/SIT Study Abroad.

Reason:

☐

I hereby withdraw permission for World Learning/SIT Study Abroad to publish my ISP/FSP on its websites and in any of its digital/electronic collections, or to reproduce and transmit my ISP/FSP electronically.

Reason:



---

Student Signature

November 15, 2018

Date

Academic Director has reviewed student reason(s) for withdrawing permission to use and agrees it does not violate the SIT Study Abroad Policy on Ethics.