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To Smear or Not To Smear? Evidence of a Failure of Implementation and Content Suitability of the 2000 National Guideline on Cervical Cancer Screening Program in Kwazulu-Natal, South Africa

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TO SMEAR OR NOT TO SMEAR?

EVIDENCE OF A FAILURE OF IMPLEMENTATION AND CONTENT SUITABILITY
OF THE 2000 NATIONAL GUIDELINE ON CERVICAL CANCER SCREENING
PROGRAM IN KWAZULU-NATAL, SOUTH AFRICA

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7 December 2006

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Abstract

The value of screening for cervical cancer has been proven; as such screening has resulted in a decrease in incidence and mortality of cervical cancer by over 80% in developed countries¹. Yet despite a screening infrastructure, cervical cancer is the most common female malignancy in South Africa², affecting 1 in ever 41 women.³ It is estimated that more than 3,400 South African women die of cervical cancer every year⁴. In the year 2000, the South African Department of Health initiated its National Guideline on Cervical Cancer Screening Program. The program, based on World Health Organization (WHO) guidelines for low-resource settings, calls for South African women to receive 3 smears per lifetime with a 10 year interval between each smear, commencing at no earlier than age 30. The ultimate goal is to screen 70% of targeted women, nationally, within 10 years of initiating the program in order to reduce the incidence, morbidity, mortality and cost of cervical cancer.⁵

In this study, I evaluate the implementation challenges and content suitability of the 2000 National Guideline on Cervical Cancer Program in KwaZulu-Natal (KZN) by triangulating the data I have collected from interviews with relevant stakeholders in the cervical cancer field, pertinent secondary sources on the topic and my general observations living and studying in KZN from the period of 8 September 2006 to 7 December 2006.

The evidence I detail suggests that the current National Guideline on Cervical Screening Program does not appear to be comprehensively implemented in KZN and may not be suitable within the context of the HIV/AIDS epidemic. In this piece, I discuss possible reasons for this alleged failure of implementation, citing evidence that 1) there are inadequate resources in the public sector, that 2) health care workers are overstrained causing i. pap smears to fall low on the list of health priorities, ii. provider attitudes that discourage clinic attendance and iii. a possible information-dissemination failure from healthcare provider to patient and that 3) there is inadequate publicity of the cervical screening program to the public at large. I then discuss data that suggests that even if implemented, the cervical screening policy may not be suitable in KwaZulu-Natal because such a substantial portion of the young female population is infected with HIV. Evidence suggests that HIV decreases the age at which women have cervical cancer, decreases the interval of time from dysplasia to cancer and increases the likelihood of false-negative results of pap smears. As such, HIV-positive women should be getting pap smears at young ages and at frequent intervals. Finally, in an epilogue, I discuss exciting new developments in the cervical cancer field.

¹ Sankaranarayanan, R., Budukh, AM. & Rajkumar, R. *Effective screening programmes for cervical cancer in low-and middle-income developing countries*. Bulletin of the World Health Organization, 2001.

² Wellensiek, N., Moodley, M. Moodley, J.& Nkwanayana, N. *Knowledge of cervical cancer screening and use of cervical screening facilities among women from various socioeconomic backgrounds in Durban, Kwazulu- Natal, South Africa*. International Journal of Gynecological Cancer 2002, 12, 376-382.

³ *National Guideline on Cervical Cancer Screening Programme*. Republic of South Africa Department of Health, 2000.

⁴ CANSA, Cancer Association of South Africa, *More services needed to fight cervical cancer* (www.givengain.com), 29/10/2006.

⁵ *National Guideline on Cervical Cancer Screening Programme*, 2000.

Introduction

Cervical Cancer and HPV infection

Cervical Cancer is the second most common cancer in women worldwide, with about 500,000 new cases and 250,000 deaths every year. Unlike most other forms of cancer, cancer of the cervix is preventable, using relatively inexpensive screening to detect and treat abnormal cervical tissue before it progresses into invasive cancer.⁶ The earlier the detection of abnormal cell tissue (known as dysplasia), the better the chances a patient has of complete recovery⁷.

Virtually all cervical cancer cases (99%) are linked to genital infection with Human Papillomavirus (HPV), which is the most common viral infection of the reproductive tract.⁸ The rate of transmission of HPV is several orders of magnitude greater than other STIs and transmission does not require full penetrative intercourse or many partners. Most HPV infections have no signs and no symptoms and most infected people are unaware that they are infected.⁹ There are 40 different genotypes of HPV that can infect the genital area of both men and women. HPV 16 and 18 are considered high-risk genotypes and are responsible for the majority of HPV-related cancers of the cervix,

⁶ *Preparing For the Introduction of HPV Vaccines: Policy and Programme Guidance for Countries*. WHO/UNFPA. Based on UNFPA/WHO Technical Consultation of HPV Vaccines and Sexual and Reproductive Health Programs held in March 2006 in Montreux, Switzerland.

⁷ CANSA, 2006.

⁸ *Preparing For the Introduction of HPV Vaccines*, March 2006.

⁹ *Preparing For the Introduction of HPV Vaccines*, March 2006.

vulva, vagina, anus and penis worldwide¹⁰. HPV genotypes 6 and 11 cause a substantial proportion of low grade cervical dysplasia detected in screening.¹¹

In most cases¹², cervical cancer develops slowly. HPV infects the cells of the cervix and causes cell dysplasia (also called cervical intraepithelial neoplasia or CIN). Cancer of the cervix develops from these dysplastic precursor lesions, progressing steadily from mild (CINI) to moderate (CINII) to severe (CINIII) dysplasia,¹³ then to carcinoma in situ¹⁴ and finally to cancer¹⁵. The direct precursor of cervical cancer is high- grade dysplasia which in 1/3 of cases progresses to cervical cancer usually over a period of 10-15 years. Around 90% of low-grade dysplasias regress spontaneously. Besides HPV other risk factors for cervical cancer include high-risk sexual activity patterns, oral contraceptive use and smoking.¹⁶

Women generally are infected with HPV in their teens, 20s, or 30s. The disease, if it persists, can take up to 20 years after initial HPV infection to develop. On the whole, cervical cancer peaks at about age 50 and severe dysplasia risk peaks at about age 35.¹⁷

Once cervical cancer develops, it starts at an in situ stage than can be treated, but then progresses to invasive disease that is always fatal where surgery and radiation therapy are unavailable¹⁸. Symptoms of late stage cervical cancer include bleeding

¹⁰ Preparing For the Introduction of HPV Vaccines, March 2006.

¹¹ Preparing For the Introduction of HPV Vaccines, March 2006.

¹² Dysplasia progresses differently in patients that are HIV positive. Such differences will be discussed extensively below. It is vital to note that the cervical cancer discussion in this section is describing the disease as an overview and assumes HIV negative status.

¹³ A new classification has recently been introduced whereby the precursors are named squamous intra-epithelial lesions (SIL) which are divided into low-grade SIL (similar to CIN1) and high grade SIL (for CIN11 and CIN111). Both classifications are used today.

¹⁴ *In situ* is latin for “in its original place.”

¹⁵ Sankaranarayanan et al., 2001.

¹⁶ *Cervical Cancer Prevention*. Reproductive Health Outlook. (<http://www.rho.org>). 18/10/2006.

¹⁷ *Cervical Cancer Prevention*. *RHO*, 18/10/2006.

¹⁸ *Cervical Cancer Prevention*. *RHO*, 18/10/2006.

between monthly periods, unusually heavy periods, pain during intercourse, bleeding after intercourse or after pelvic exam and bleeding after menopause¹⁹.

To detect cellular dysplasia, a Papanicolaou (Pap) smear is performed²⁰. A Pap smear is a cytological test designed to detect abnormal cervical cells. The procedure involves scraping cells from the cervix and then smearing and fixing them on a glass slide. The slides are sent to a cytology laboratory and evaluated by a trained cytologist or cytotechnician who determines the cell classification.²¹ If abnormalities are found, a colposcopy is performed to determine the cause of the abnormalities. A colposcopy is a visual examination of the cervix and is a relatively simple and painless procedure that lasts approximately 10 minutes.

Cervical Cancer in the Developing World

While frequently repeated cytology screening has led to an 80% decline in cervical cancer mortality in the developed world, cervical cancer remains an important public health problem among adult women in developing countries. Approximately 190,000 women in developing countries die from cervical cancer every year. It has been estimated that only 5% of women in developing countries have been screened for cervical

¹⁹CANSA, 29/10/2006

²⁰ There are other ways in which cellular dysplasia can be detected. One relatively novel way is the use of acetic acid to detect abnormalities. This may be extremely beneficial in low resource settings. Please see the Epilogue for a further discussion on the use of acetic acid in cervical cancer screening.

²¹ *Cervical Cancer Prevention, Fact Sheet*. Alliance for Cervical Cancer Prevention. (www.path.org), 22/11/06.

dysplasia in the past 5 years compared with 50% from developed countries²².

Furthermore, developing countries have access to only 5% of global cancer resources²³.

It is generally undisputed that cervical screening fulfills the criteria of an effective screening program, which includes cost effectiveness, reduction of incidence of a disease and reduction of morbidity and mortality from a disease²⁴. Yet due to more limited health care resources, developing countries often cannot afford the model of frequently repeated screening of a wide age range of women that are used in developed countries. In such resource limited settings, the World Health Organization (WHO) supports the concept of reducing the number of smears per women per lifetime in favor of more women in the population having fewer smears. According to the WHO, it is more realistic and effective to target a national screening program to high risk women once or twice in their lifetime using a highly sensitive test, with an emphasis on high coverage of the target population.²⁵

South Africa and Cervical Cancer

In South Africa, despite a screening infrastructure, cervical cancer is the most common female malignancy affecting 1 in every 41 women²⁶. The majority of South African women have never been screened for cervical cancer and only present at facilities with advanced staged disease²⁷. Cervical cancer accounts for 17% of all cancers in South

²² *Cervical Cancer Prevention. RHO, 18/10/2006.*

²³ Smit, J., Beksinska, M., Ramkissoo, A., Kunenei B., & Penn-Kekanai, L. *Chapter 5: Reproductive Health. South Africa Health Report 2004.*

²⁴ Wellensiek et al., 2002.

²⁵ Sankaranarayanan et al., 2001.

²⁶ *National Guideline on Cervical Cancer Screening Programme., 2000.*

²⁷ CANSA, 29/10/2006.

Africa and has an incidence of approximately 30 in 100,000 women²⁸. It is estimated that more than 3,400 South Africans die every year from cervical cancer and it is the leading cause of cancer deaths in South African women.²⁹

Like many other health-related services, access to cervical screening and rates of cervical cancer incidence in South Africa are divided along racial lines. A 2004 study found that over 90% of white women and only 5% of African women had accessed cervical screening in the past 10 years³⁰. Furthermore, it is estimated that 1 in 25 African women will develop cervical cancer in her lifetime, whereas 1 in 34 colored women and 1 in 81 white and Asian women will develop the disease^{31, 32}.

Over South Africa's history, cervical cancer policies have evolved with time. In the 1970s the Department of Health advocated that pap smears be performed if the cervix of a patient 'looked' abnormal. This policy was quickly abandoned because by the time a clinician would detect an abnormality in the cervix, the cancer was already advanced. In the early 1980s, the availability of pap smears decreased because cervical cancer deaths were decreed to be less serious than other health challenges. In 1989, the policy to screen women once in their lives at age 40 was initiated, but no coordinated mechanism to implement this policy was ever developed.³³

²⁸ Wellensiek et al, 2002.

²⁹ CANSA, 29/10/2006.

³⁰ Smit et al., 2004.

³¹ CANSA, 29/10/2006.

³² On a national level, there is still no statistical data collected in South Africa on the number of women screened for cervical cancer, the percent of women detected with abnormal smears or the percent of women treated or referred for cervical cancer treatment. Smit et al., 2004.

³³ Cervical Cancer Prevention, RHO, 18/10/2006.

In the year 2000, the South African Department of Health initiated its National Guideline on Cervical Cancer Screening Program³⁴, which has not changed to the present day. The program is largely based on the International Agency for Research on Cancer (IARC)³⁵ guidelines³⁶. The program states that South African woman will receive 3 Pap smears per lifetime with a 10 year interval between each smear, commencing at no earlier than age 30. The ultimate goal is to screen at 70% of women, nationally, within this target age group within 10 years of initiating the program. Its objectives are to reduce the incidence of carcinoma of the cervix, primarily by detecting and treating the pre-invasive stage of the disease, to reduce the morbidity and mortality associated with cervical cancer and to ultimately reduce the excessive expenditure of scarce health funds currently spent on the treatment of invasive cancer of the cervix. The National Guideline asserts that this policy reflects the best attempt to reduce the incidence and mortality of cervical cancer by more than 60 percent and is based on “the best available evidence in low-resource settings.”³⁷

This short study attempts to critically examine the current screening program as it approaches its seventh year of initiation. The analysis relies on interviews conducted with a diverse group of relevant stakeholders throughout KwaZulu-Natal, several pertinent secondary sources and my experiences as a student studying and living in Durban. Throughout this study, I will argue that the Department of Health’s 2000

³⁴ Please see Appendix D for a full copy of the National Guideline on Cervical Cancer Screening Programme.

³⁵ The IARC is a department of the WHO.

³⁶ The South African Institute for Medical Research, Women’s Health Project, Cancer Association of South Africa, National Institute of Virology all helped develop the National Guideline.

³⁷ *National Guideline on Cervical Cancer Screening Programme*, 2000.

Cervical Cancer Screening Program seems to have largely failed in KZN³⁸ because it appears not to be comprehensively implemented in the province and may be unsuitable within the context of the HIV/AIDS epidemic. I will begin, in Part One, by describing the apparent inability to implement the screening policy into practice in KZN and provide some of the possible reasons behind this failure of implementation. Then in Part Two, I will describe why, if implemented in its current form, the program would likely still be unsuccessful in achieving its goals because of a well-documented association between cervical cancer and HIV/AIDS.

³⁸ Due to the fact that my observations and experiences were limited to KwaZulu-Natal, I cannot reasonably comment on whether or not the program could potentially be successful in other parts of South Africa or in other developing countries. It is vital to note that many of my primary and secondary sources spoke of problems with the cervical cancer screening policy in South Africa as whole, and not just problems specific to KZN. As the largest province in the country with 9 million inhabitants, and as an area disproportionately burdened with many of the countries worst public health problems, many challenges of policy implementation described as issues in the whole of South Africa are likely relevant to KZN.

Methodology

All data, both primary and secondary used in this study was collected in KwaZulu-Natal, South Africa from the period of 8 September 2006 to 7 December 2006. The interviews with relevant stakeholders in the cervical cancer field were conducted in various sites in Durban, South Africa from the period of 13 November 2006 to 1 December 2006. The data from each primary source used in this study was collected in a unique way, as each source is unique. The context in which each piece of evidence was collected is an important factor in understanding that evidence. The details behind the data of each primary source in the order I met with them are described below³⁹.

Ruby Makhathini- Ruby is a 62-year old Zulu woman who lives in a government subsidized home in Cato Manor, Durban, South Africa. Ruby did not attend university, currently does not work and had 2 children in her lifetime, but lives only with her grandson Bhuwa today. All information I obtained from Ruby was through casual conversations throughout the time that I lived in her household between 9/9/06 to 4/10/06,⁴⁰ as well as a visit on her birthday on 02/11/06. Ruby and I would talk about a myriad of topics while she cooked and cleaned or while we were watching TV. All the data used in this study was obtained when Ruby and I were conversing alone.

Manto Tshabalala-Msimang- Dr. Manto Tshabalala-Msimang is a South Africa's Minister of Health. On 6 October 2006 she spoke at a community event in Mpumalanga to commemorate the Breast, Cervical and Prostate Cancer Month. I obtained the contents of her speech on the Department of Health website (www.doh.gov.za).

Mark Colvin- Mark Colvin is an epidemiologist affiliated with the University of KwaZulu-Natal (UKZN). The data I obtained from Mark Colvin was during his two power-point lectures to 17 American students from the School of International Training on *Public Health and Epidemiology* and on *HIV and AIDS in South Africa* on 19/09/2006 and 27/10/2006 respectively.

Catherine Burns- Catherine Burns is a historian at UKZN. The data I obtained from Catherine Burns was during her lecture to 17 American students from the School of International Training on the *History of Health in South Africa* on 26/09/2006.

Sister Thandanani Simelani- Sister Simelani is a South African nurse. The data I obtained from Sister Simelani was when she came and lectured to the School for International Training students in the Community Center in Nyoni on 13/10/06 after a full days work in the clinic. Nyoni is a rural town about 90 kilometers north of Durban.

Dr. Duze- Dr. Duze is a South African doctor who grew up in a rural area. The data I obtained from Dr. Duze was when he came and lectured to 17 American students from the School of International

³⁹ Please see the *Limitations of the Study* section for predisposed and researcher-influenced biases of each source.

⁴⁰ I lived with Ruby during the 'homestay' portion of the School for International Training (SIT) Study Abroad Program I attended in South Africa. It is important to note that I, as well as all other SIT students, was assigned to whom we would be living with in Cato Manor, and did not get to choose our home.

Training on 02/11/06 on his experiences as a doctor in a rural hospital. The lecture took the form of a question-answer session in which students would ask Dr. Duze to discuss a particular topic.

Dr. Amo Jordaan—Dr. Amo Jordaan is the Head of the Radiation Oncology Department at Addington Hospital. I met with Dr. Jordaan in his office at the Oncology Clinic of Addington Hospital on 15 November 2006. At Addington, Dr. Jordaan sees women who have already been diagnosed with cervical cancer, and as such, has insight into the factors behind getting the disease. I obtained data from Dr. Jordaan when sitting across from him at his desk.

Addington Hospital- Addington Hospital is 524 bed, 2,200 staffed district and regional hospital in South Beach, Durban. I arrived at the hospital in order to meet with Dr. Jordaan at around 12:00 on 15 November 2006 and had to walk through several corridors in order to reach the Oncology Clinic where I was to interview Dr. Jordaan.

Mags Beksinska- Mags Beksinska is Director of the Durban office of the Reproductive Health and HIV Research Unit (RHRU), whose main office is based at the University of Witwatersrand in Johannesburg. The RHRU is one of the foremost South African Institutions engaged primarily in research and training in the field of reproductive health. It is also affiliated with the WHO as a collaborating center. I interviewed Mags Beksinska in her office at the Durban RHRU headquarters in Westville. Mags Beksinska does work in the Antiretroviral (ARV) rollout centers and has insight into cervical cancer screening in these clinics.

Gender AIDS Forum (GAF)- The Gender AIDS Forum is a Durban- based South African activist NGO, committed to advocating the links between gender and HIV/AIDS. GAF researches many reproductive health issues including cervical cancer. I went to GAF on 20 November 2006 after I met one of their researchers, Elizabeth Elston, who said they may have helpful data in their resource room as they have worked on cervical cancer screening in the past. I spent the day researching documents written by GAF in their resource room with direction from Elizabeth Elston as of where to look.

Charlie Roberts- Dr. Charlie Roberts is a General Practitioner at Entabeni Hospital. I interviewed Dr. Roberts over the phone on 21 November 2006 asking him questions about cervical cancer screening in the *private* sector and his general insight as a doctor about the challenges in the field at the present time.

Paula Warren- Dr. Paula Warren is a 26- year old General Practitioner at Entabeni Hospital. Dr. Warren spent her community service year⁴¹ in a rural clinic in Northern KwaZulu-Natal in 2005. In this clinic, she was working with another community service year doctor and four nurses. I interviewed Dr. Warren at her medical practice at Entabeni Hospital.

Entabeni Hospital- Entabeni is a private hospital in Durban, South Africa. It is a member of Life Healthcare, one of the largest private hospital groups in South Africa with 62 acute care facilities across the country. I went to Entabeni Hospital on 23 November, 2006 and waited briefly in waiting room of the Central Medical Suite before meeting with Dr. Warren.

Joel Perry- Joel Perry is the Cancer Association of South Africa's (CANSA) Director of Health Programs. CANSA is an NGO who goal is to substantially reduce the impact of cancer by promoting health in all communities within South Africa, through advocacy and the sustainable facilitation of research, prevention, early detection and care.⁴² I spoke briefly with Joel Perry on the phone, but as he did not have the time to meet with me he asked me to e-mail him my questions. He responded an hour later with detailed answers.

Dr. G.- Dr. G is a black, male Gynecologist working at the Obstetrics and Gynecology Department of the Inkosi Albert Luthuli Hospital in Central Durban. I use "Dr. G." in order to keep his identity hidden. The data I obtained from Dr. G. was in the morning of 30 November 2006 when I observed him at work in a consultation room of the Obstetrics and Gynecology clinic at Inkosi Albert Luthuli Central Hospital. In the time that I was in Dr. G's consultation room he saw three patients. The first patient who came in was menstruating, so she was given an appointment to come back the next week. The second patient to come in was referred to the wrong department by a doctor at King Edward VII Hospital and was thus not seen. The third patient was a 26-year old Zulu woman who was HIV positive and was referred for treatment of high-grade cervical lesions from the Medical Research Council Clinical Trials. All patients gave their consent that I could be sitting in on their consultation.

⁴¹ After finishing Medical School, South African's must work one 'community service' year in the public sector before they can qualify as doctors.

⁴² Found at www.givengain.com.

Dr. Z.- Dr. Z is a black, female Oncologist working at Obstetrics and Gynecology Department at Inkosi Albert Luthuli Hospital in Central Durban. I use “Dr. Z.” in order to keep her identity hidden. The data I obtained from Dr. Z. was in the morning of 30 November 2006 when I observed her at work in a consultation room of the Obstetrics and Gynecology clinic at Albert Luthuli. In the time that I was in Dr. Z’s consultation room she saw one patient, a white woman who had cancer in her right ovary and had recently undergone an operation. The patient gave her consent that I could be sitting in on her consultation.

Inkosi Albert Luthuli Central Hospital- Inkosi Albert Luthuli is well-resourced tertiary and quaternary hospital open to patients in Central Durban. It is open for all people needing late-stage medical treatment from the whole of KwaZulu-Natal and parts of the Eastern Cape. After describing in detail the purpose of my study, I received permission from the head of the Obstetrics and Gynecology clinic to shadow doctors in the hospital on the morning of 30 November 2006. I also received permission to use the name of the hospital in this study. I sat first in the consultation room of Dr. Z around 10:00 with one patient and then moved to Dr. G’s consultation room for 2 hours during which he saw 3 patients.

Manivasan Moodley- Dr. Manivasan Moodley is a doctor and researcher at Department of Obstetrics and Gynecology, Nelson R. Mandela School of Medicine. Dr. Moodley is my advisor for this project. We corresponded through telephone and e-mail before we met on 1 December 2006. I interviewed and discussed cervical cancer screening issues—particularly the link between HIV infection and cervical cancer—with Dr. Moodley across from his desk at his office at the Nelson R. Mandela School of Medicine.

I also rely significantly on the secondary sources that inform this paper. My secondary sources are limited to nineteen articles and documents obtained through search engines on the World Wide Web and through research in the GAF resource room. In addition, several pertinent documents were given to me when I met with interviewees, who thought that certain papers would be applicable to my study. For a list of each secondary source and a brief note on how it is relevant to the study, please see the *Literature Review*.

Literature Review:

Anderson J., Shah, K., Paramsothy, P., Heilis, C., Jamieson, D. & Duen, A. *Predictive value of pap smear screening in HIV infected and high risk HIV uninfected women*. 14th International AIDS Conference, Barcelona, Spain. July 7-12, 2002. **This article provides evidence that HIV positive women with CD4 less than 500/mm³ are more likely to have false negative pap smears and screening at shorter intervals may be warranted.**

Barnabas L., Madlala N., Magwaza T., Maphumulo T., Mcanyana N, Mlambo R, Mpungose, G., Ngidi C., Tallis V. & Tolofi, R..“*Things are so wrong out there*”: *The experiences of women living with HIV & AIDS in accessing sexual and reproductive health & rights in KwaZulu Natal, South Africa: A study with women living with HIV and AIDS*. 24, January 2006. **This article highlights women’s difficulties in accessing their reproductive and sexual rights within the public health sector. The comments and experiences of women throughout KwaZulu-Natal are used throughout this study.**

CANSA, Cancer Association of South Africa, *More services needed to fight cervical cancer* (www.givengain.com), 29/10/2006. **This website provides facts and figures specific to South Africa on cervical cancer.**

Cervical Cancer Prevention, Fact Sheet. Alliance for Cervical Cancer Prevention. (www.path.org), 22/11/06. **This website provided information about the cytology laboratory where pap smear results are analyzed.**

Cervical Cancer Prevention. Reproductive Health Outlook. (<http://www.rho.org>). 18/10/2006. **This paper is used throughout the piece. It provides facts and figures about cervical cancer both in general and specific to South Africa. It is used to provide a history of cervical cancer screening within the South African context. The paper is also cited in the discussion of the natural progression of cervical cancer and provides evidence of the link between HIV and cervical cancer.**

Clark B. & Chetty, R. *Postmodern cancer: the role of human immunodeficiency virus in uterine cervical cancer*. *Molecular Pathology*, 2002 Feb;55(1):19-24. **This paper found that HIV causes more rapid progression to high grade and invasive cervical cancer lesions.**

Cooper, D., Marroni, C., Orner, P., Moodley, J., Harries, J., Cullingwath L. & Hoffman, M. *Ten Years of Reproductive Health Policy and Status*. *Reproductive Health Matters* 2002, 12 (24): 10-85. **This article documents the changes in reproductive health policy since the advent of democracy in South Africa. It briefly discusses cervical cancer as one of the key areas of sexual and reproductive health. It is cited in the concluding discussion of this study as it provides evidence of the progressive reproductive health policies in South Africa.**

Danso, D., Lyons, F. & Bradbeer C. *Cervical Screening and Management of cervical intraepithelial neoplasia in HIV positive women*. Int J STD AIDS. 2006 Sep;17(9):579-84. **This paper discusses a study in London which matched AIDS and cancer registries and found the average age for carcinoma in situ in HIV-infected women and HIV-negative women to be 32.7 and 47.5 respectively. It is also used as evidence of the rapid progression of premalignant cervical lesions to invasive cervical cancer in HIV-infected women.**

Dorrington, R., Johnson L., Bradshaw, D. & Daniel, T. *The Demographic Impact of HIV/AIDS in South Africa*. National and Provincial Indicators for 2006. Cape Town: Center for Actuarial Research, South African Medical Research Council, and Actuarial Society of South Africa. **This paper is the source of all the HIV/AIDS statistics that appear in this study.**

False-negative Pap test rate high. Newline People AIDS Coalit N Y. 1999 Apr-May:31. **This paper provides evidence that HIV- positive women are more likely to have false negative pap smears.**

Gichangi PB, Bwayo J, Estambale B, De Vuyst H, Ojwang S, Rogo K, Abwao H & Temmerman M, *Impact of HIV infection on invasive cervical cancer in Kenyan women*. AIDS. 2003 Sep 5;17(13):1963-8. **This paper provides evidence that there is an accelerated clinical progression of premalignant cervical lesions to invasive cervical cancer in HIV-infected women.**

HIV/AIDS Clinical Care Guidelines for Adults: HIV/AIDS & STD Directorate, Department of Health, 2003. **These are the Department of Health Guidelines for clinical care of HIV/AIDS patients. They provide evidence that the Department recognizes an association between cervical cancer and HIV when treating female HIV/AIDS patients.**

Smit, J., Beksinska M., Ramkissoon, A., Kunenei, B. & Penn-Kekanaai, L. *Chapter 5: Reproductive Health*. South Africa Health Review 2004. **This 2004 South Africa Health Review contained a chapter on Reproductive Health which contained a section on cervical cancer. The chapter is used as evidence for a lack of advertising of cervical screening services by public health facilities. It is also used to describe the key challenges in translating the 2000 Cervical Screening Program into effective service.**

National Guideline on Cervical Cancer Screening Programme. Republic of South Africa Department of Health, 2000. **This is the document detailing the Department of Health's National Guideline on Cervical Cancer Screening Program. It can be found in Appendix D.**

Preparing For the Introduction of HPV Vaccines: Policy and Programme Guidance for Countries. WHO/UNFPA. Based on UNFPA/WHO Technical Consultation of HPV Vaccines and Sexual and Reproductive Health Programs held in March 2006 in

Montreux, Switzerland. **This document provides some of the background facts and figures about cervical cancer. It also describes the recent introduction of HPV vaccines against cervical cancer detailed in the epilogue of this study.**

Sankaranarayanan, R., Budukh, AM. & Rajkumar, R. *Effective screening programmes for cervical cancer in low-and middle-income developing countries*. Bulletin of the World Health Organization, 2001. **This paper provides an explanation of the factors contributing to the WHO's cervical cancer screening recommendations in low-resource settings. It also provides some background facts and figures about cervical cancer and its progression.**

Vazquez E, *The danger of using only one pap smear*. Posit Aware. 1999 May-Jun;10(3):23. **This paper provides evidence that HIV- positive women are more likely to have false negative pap smears.**

Wellensiek, N., Moodley, M. Moodley, J.,& Nkwanayana, N. *Knowledge of cervical cancer screening and use of cervical screening facilities among women from various socioeconomic backgrounds in Durban, Kwazulu Natal, South Africa*. International Journal of Gynecological Cancer 2002, 12, 376-382. **This paper supplied evidence that providing a cervical screening service is not enough to ensure successful uptake of cervical cancer screening. It is used in this study as evidence of an information-dissemination failure from provider to patient.**

Findings and Analysis

PART ONE: A Failure of Implementation

“Readiness for implementation is still a challenge for the health services in the public sector. As a result cervical screening is a far cry from what is proposed”-Joel Perry, CANSA Director of Health Programs⁴³

As stated above, the ultimate goal of the 2000 Cervical Cancer Screening program is to screen 70% of women, nationally, in the target age group of 30-50 years within 10 years of initiating the program. Yet based on the data obtained throughout my study it seems apparent that, as its approaching its seventh year of induction, the South African cervical screening program is not being comprehensively implemented into practice.

The evidence that I found of a widespread belief in the failure of the cervical screening policy’s implementation was extensive. When meeting with Dr. Amo Jordaan, Head of the Radiation Oncology Department at Addington Hospital, he stressed to me that “the majority of South Africans are not screened today, especially not the ones in need⁴⁴.” Dr. Paula Warren, a General Practitioner who spent her community service year working in a rural clinic in KZN, put it even more bluntly, “the 30-50 policy is not enforced; *not at all*. Most of the women I saw [in the clinic] never had a pap smear in their lives⁴⁵.” In a 2004 study conducted throughout KZN only 31% of public sector facilities were found to have cervical screening services, lower than the national average

⁴³ Joel Perry. Cancer Association of South Africa (CANSA) Director of Health Programs. *Interview*. 27/11/06. All phrases found in quotation marks are direct quotations.

⁴⁴ Dr. Amo Jordaan. Head of Oncology, Addington Hospital. *Interview*, 15/11/06.

⁴⁵ Emphasis added. Dr. Paula Warren, General Practitioner, Entabeni Hospital. *Interview*, 23/11/06.

of 49.6%. And the 2004 South African Health Review (SAHR) stated that “although screening has been provided through the South African public sector health facilities for many years, there has been minimal impact on cervical cancer morbidity and mortality because of *limited screening* of the population at risk⁴⁶.”

While speaking to relevant stakeholders and reading pertinent documents throughout my study, I have found evidence that the failure of implementation of the cervical cancer screening policy appears to be a result of many factors. These include 1) resource shortages in public sector facilities, 2) the consequences of a system with overstrained health care providers and 3) a lack of public education on the value and purpose of cervical screening.⁴⁷

1. Inadequate Resources

“Even if you perform a pap smear, how do you manage a patient with no resources?”-

*Dr. Charlie Roberts, General Practitioner, Entabeni Hospital*⁴⁸

To have an effective cervical cancer screening program, you need the appropriate screening resources. The 2004 SAHR asserted that “effective implementation [of the 2000 Cervical Screening Program] has been hampered by general weakness in the public

⁴⁶ Smit et al., 2004.

⁴⁷ There are other factors that may contribute to the cervical screening uptake failure such as a patients own personal or cultural beliefs that prevent her from coming into the clinic, ignorance of the issues among healthcare providers, a lack of public will to get screened etc. Due to the limited nature of this study I will only go into the factors listed.

⁴⁸ Dr. Charlie Roberts, General Practitioner, Entabeni Hospital. *Interview*, 21/11/06.

health system stemming from lack of financial and human resources.” Throughout my work, I have found substantiation to the resource-deficiency claim.

My interview with Dr. Warren shed light on one of the most striking indications of the scarcity of resources in a clinic. During Dr. Warren’s year of community service⁴⁹, she worked in a rural clinic in northern KZN for 12 months. I asked her about how often and to whom the Sisters⁵⁰ would give pap smears to in the clinic. Dr. Warren explained:

While we would try our best it was just impossible. First of all, the lab cannot possibly cope with the number of pap smears you would need. And even if it did, it would still be impossible. The best we could do would be 3 paps in a day from an instrumental point of view, we only had 3 speculums⁵¹ and those 3 we had to reserve for the women in ARV trials, we would just do the first 3 women that would come in. The biggest problem was that the 3 speculums were different sizes. There was one tiny one for the younger girls; a medium sized one and a ‘monster for the big mamas.’⁵² But you couldn’t chose which one you would use, you would just have to take the first one that was available, so a little girl was getting a gigantic speculum and a huge women was getting a tiny one. They were so uncomfortable it was hard to watch. You could only imagine that they would never want to get a Pap smear again.⁵³

⁴⁹ In the year 2005.

⁵⁰ ⁵⁰ “Sister” is a term for nurse in South Africa.

⁵¹ A speculum is the instrument used during a pap smear to widen the opening of the vagina so that the cervix is more easily visible. To sterilize a speculum it must be sent off to a facility that sterilizes medical equipment.

⁵² This was a direct quote from Dr. Warren.

⁵³ Paraphrased from Dr. Warren’s words, 23/11/06. All italicized phrases attributed to individuals throughout this work are paraphrases. I had my pen and paper out during most interviews, but I tried my best to get down the overall essence of comments and sometimes did not pick up the exact words of my interviewees.

In this experience, Dr. Warren brings up several resource shortages that are supported by other sources. Dr. Warren first states that “the lab” could never cope with the number of pap smears that the clinic needed to be performing. The lab she is referring to here is the national cytological lab that reports the results of pap smears. In a similar vein, the 2004 SAHR lists as one of its major challenges in translating national cervical cancer policy into effective service as “the limited capacity of national cytological labs⁵⁴.” Professor Jordaan, too, emphasized a need for more people to work in these labs so that we could “actually cater for a greater number of pap smears,”⁵⁵ and Mags Beksinka claimed that, *our system in South Africa is very slow, there are many steps along the way in which the system fails. Not only to you have to get someone skilled to provide the pap, you have to get someone in a lab to get results. A lot of clinics struggle with the next step, if they were to implement the policy it would create a whole new list of challenges.* From these statements, it seems as though one of the many obstacles preventing effective implementation of the national cervical cancer screening policy is the inadequate capacity of the cytological labs to determine the cell classification.⁵⁶

Another resource problem seems to be an equipment shortage, as described by Dr. Warren when she attributed the lack of speculums as a barrier to cervical care. Data from a 2003 baseline survey of STI and HIV services, found that 88.2% of South Africa’s public sector facilities contained sterile speculums. Broken up by province, KZN

⁵⁴ Smit et al., 2004.

⁵⁵ Professor Jordaan, 15/11/06.

⁵⁶ It is also important to note that the 2004 SAHR included inadequate infrastructure to transport specimens to these labs as another key challenge in translating national cervical cancer screening policy into effective service. Smit et al., 2004.

registered 80%, the lowest of all nine provinces⁵⁷. At first glance it may seem that 80% is a relatively high number, and a reasonable person could take this to mean that a good proportion of public sector facilities in KZN have the ability to perform pap smears⁵⁸, but Dr. Warren's experience sheds a bit of light on this statistic. Dr. Warren's clinic would likely have registered as one of the public sector facilities with sterile speculums—as there were 3 in the facility, yet it is evident from our discussion that these sterile speculums were *not* sufficient to perform anywhere near the amount of pap smears necessary to effectively implement the cervical cancer policy. A much better indicator would be statistic on how many pap smears are done in public sector facilities each day, but the Department of Health does not have such statistics⁵⁹.

Evidence of an equipment- shortage also came up at Inkosi Albert Luthuli Central Hospital, a tertiary and quaternary hospital in the center of Durban. The gynecologist I observed told me that, at Albert Luthuli, he had all the necessary resources to perform the number of pap smears and coloscopies needed per day. Yet he explained that on Fridays, when he worked King Edward VII Hospital, an older tertiary facility that is the second largest hospital in South Africa, it was a much different story. At King Edward health care providers often lacked enough speculums and spatulas to perform the needed number of pap smears and, according to Dr. G⁶⁰, often had to resort to recycling materials instead of going through the time-consuming process of sterilization⁶¹.

⁵⁷ Smit et al., 2004.

⁵⁸ This is assuming that if a clinic has a speculum it would also have a spatula and a glass slide, which according to Dr. Jordaan, is very likely.

⁵⁹ Smit et al., 2004.

⁶⁰ I call this doctor, Dr. G, in order to protect his identity.

⁶¹ Dr. G, 30/11/06.

Another resource-gap delineated by many of the relevant stakeholders I spoke with was the lack of trained *human* capacity to implement the cervical screening program. Dr. Amo Jordaan explained that you would *quite literally need to have a new hired person working for 24 hours a day doing pap smear after pap smear in each clinic to get anywhere near the amount that should be getting done.* He also emphasized that trained nurses have a high turnover rate, usually staying in clinics for about 5 years and then going into “the private sector or Saudi Arabia where they get paid more.”⁶² Mags Beksinska, director the of the Durban office of the Reproductive Health and HIV Research Unit (RHRU), explained one of the obstacles to screening she saw was that in many of the Antiretroviral (ARV) clinics she attended⁶³, there were no “free hands” available to provide pap smears⁶⁴. And the 2004 SAHR listed “limited number of trained service providers in the public sector” as one of the key challenges in implementing the national cervical screening policy⁶⁵.

The evidence delineated above seems to uphold Joel Perry’s claim that “the biggest challenge we face with cervical cancer screening today is the readiness of primary healthcare services⁶⁶.” The above evidence suggests that many of the target women may not be appropriately screened because of a resource-shortage in public facilities.

2. *Overworked, Overstrained Healthcare Providers*

⁶² Dr. Jordaan, 15/11/06.

⁶³ ARV clinics are clinics designated by the Department of Health to provide ARVs to HIV- positive South Africans with CD4 counts under 200.

⁶⁴ Beksinska, Mags. Reproductive Health Unit, University of the Witwatersrand, Durban Office. *Interview*. 17/11/06.

⁶⁵ Smit et al., 2004.

⁶⁶ Joel Perry, 27/11/06.

Another key reason for the failure to implement the cervical screening policy seems to be the environment in which many public-sector health care providers work. Healthcare providers in the public sector seem to be overworked and, consequently, exhausted⁶⁷. This was seen quite strikingly, in Nyoni⁶⁸, when Sister Thandanani Simelani, Senior Sister at Wangu Clinic, came and spoke to School for International Training (SIT) students about her experiences as a healthcare provider. She described how she worked with 3 other nurses. Together, the four Sisters are responsible for the primary healthcare of approximately 18,000 people. They see around 2, 600 patients every month! At the end of her work day, it was visibly difficult for Sister Simelani to walk across the street to where she was to lecture the SIT students. She mentioned how tired she was several times before and after her talk and chose to sit down to lecture, citing the reason for her exhaustion “a long day’s work.”⁶⁹ The Sisters at Wangu have no X-ray lab, no doctor to consult and must transport blood to the nearest hospital whenever they need it to be checked.⁷⁰

Yet the exhausting work environment in public facilities does not seem to be limited to the more rural areas. Walking into Addington Hospital, a 524 bed, 2,200 staffed district and regional hospital in South Beach, Durban, I was shaken by the massive number of people just waiting to be treated. The hospital lobby was full of approximately 200 people sitting in worn-out chairs, many staring into space as if they had been there for hours. I asked one man how long he had been waiting, he said he had been in line

⁶⁷ Duze, Dr. Principle Medical Officer, Stanger Hospital. *Lecture, Experience of a Doctor in a Rural Clinic*, 06/11/06.

⁶⁸ Nyoni is a rural town, about 90 kilometers north of Durban.

⁶⁹ Sister Thandanani Simelani, Senior Sister at Wangu Clininc, Nyoni. *Lecture*, 13/10/06.

⁷⁰ Sister Simelani, 13/10/06.

since 6:00 in the morning—the time was 12:30. When I made my way to the Oncology clinic to meet with Dr. Jordaan, I had to wait in the waiting room as he was still seeing patients. I waited for an hour along with about 40 other women. During the hour I observed nurses bringing in several women in and out of the clinic, outwardly trying their best to get as many patients through as possible. I noticed a room designated as STAFF ONLY, which seemed to be place in which nurses could relax and have some tea or coffee. Yet there was not one healthcare provider resting in that room. One nurse was limping down the hallway as if something was wrong with her leg, but kept calling women in from the waiting room and struggled to walk them into another room, where she would disappear until ready to call the next women in to be attended to. I asked the older woman next to me who had been there before I came and was still waiting as I was leaving, if she had made an appointment at the clinic for that day. She had. If most of these people--the 40 or so in the Oncology clinic, the hundreds in the lobby and the countless others in other wards of the facility-- did in fact make appointments for that day, this means that the hospital is deliberately intending to see this many patients per day.⁷¹ While this is likely a reflection of the great demand for public health facilities and the great need for care, it may also be an eye-opening illustration of how much service Addington health care workers are expected to provide day after day.

At Albert Luthuli, some of the healthcare providers I interacted with also seemed to be overstrained. When I entered Dr. Z⁷²'s Oncology consultation room she quickly sat

⁷¹It seems very likely that all these people made appointments. I say that this because of an experience I had with Ruby Makhathini during the period that I lived in her home. When she told me the night before that she was going to wake up at 4 in the morning in order to get to the clinic early to get a “good place in line,” I asked her if she had an appointment. Shocked at such a question, she told me of course she did, but so did everyone else and she wanted to be among the first to be seen. She did not come home until 5 in the afternoon.

⁷² Dr Z is another doctor from Albert Luthuli. I call her Dr. Z to protect her identity.

down and said to a nurse “Oh I’m just so busy I don’t know where to be. There is a lot to do!” And when the patient entered the room the doctor turned to her and made a comment about how hot it was outside already, even though it was only 10 am. The patient responded that she was cold already, as she had been waiting inside the hospital in line to be seen since 5:30 in the morning.⁷³

Evidence seems to point to this demanding workload of the public sector healthcare workers as another potential reason behind the alleged implementation failure of the 2000 Cervical Screening Program. Data obtained throughout my work has led support to the idea that the stressful work environment experienced by public healthcare workers often causes i) pap smears to plummet to the bottom of healthcare worker’s priorities ii) a negative health care worker attitude toward patients that discourages them to come back to clinics in general or if screened to request a smear in the future and iii) a cervical cancer screening information-dissemination failure from healthcare provider to client, which may lead to inadequate uptake of screening by the patient.

i. Pap smears as a low priority

“When you have 50-60 very sick patients waiting in line outside, who cares about pap smears?”- Dr. Paula Warren⁷⁴

Though pap smears seem to fit directly within South Africa’s 1994 decision to focus on primary rather than curative healthcare⁷⁵, it appears as though a large majority

⁷³ Inkosi Albert Luthuli Central Hospital, *Observation*. 30/11/06.

⁷⁴ Dr. Paula Warren, 23/11/06.

⁷⁵ As they are a way to *prevent* cervical cancer before it becomes invasive and must be *cured*.

of primary care facilities are still forced to focus on curative care⁷⁶. As patients often present at late stages of disease, healthcare providers are compelled to tend to those most in need at the clinics, placing routine primary services such as pap smears on hold⁷⁷. “Doctors and nurses are too busy,” explained Mags Beksinska when responding to a question about how often clinics provide routine pap smears, “if there is a specific reason for it they might screen, but there is no routine program going on like you must have one [a pap smear] every few years⁷⁸.” Dr. Jordaan agreed. When asked if he believes that patients are routinely screened for cervical cancer in the public sector, he responded, *No, nurses are much too busy, they see 100s of patients a day, they won't perform paps regularly, they are too busy processing very sick patients.* And an experience that Dr. Warren relayed to me underscored the demanding conditions of some public sector workers, and where that puts cervical cancer screening on the list of priorities for many of these providers.

There was one night in which I and the other community service year doctor were working and we had to do an emergency c- section. I had already done hundreds of c-sections, but none quite this challenging. Just as we were to begin, the generator completely broke and we had no electricity and couldn't see at all. We were so nervous and started praying, thinking that this woman and her baby were going to die. We called in the cleaning lady and had her hold a lantern over us and began to work. When the baby came out, she needed emergency surgery and the mother was loosing blood very fast. The other doctor began to take care of the mother and I was working on the baby but I couldn't see a thing so I cut a very crooked incision in her artery. Then the mother needed both of our care so I ran to her and the

⁷⁶ Smit et al., 2004.

⁷⁷ Wellensiek et al, 2002.

⁷⁸ Mags Beksikska, 17/11/06.

cleaning lady held the artery of the baby closed with a clamp. After the mother was recovering, I went back to the baby and managed to stitch her up in the dark, also crookedly, and she too, miraculously, survived. And experiences like this one were not rare there; we dealt with emergencies every day. It was so stressful. Do you see why pap smears are not one the top of everyone's list of things to do?

Dr. Warren's story illuminates the kind of stress-inducing conditions in which she worked during her year in the public sector and where this places pap smears on those who work in such condition's to-do lists. It seems, based on the above evidence, that many women are not getting pap-smears in public sector facilities throughout KZN partly because the system is so overstretched with sick patients needing more immediate, curative care. In such circumstances, the routine cervical screening required by the screening program is simply not a principal concern.

ii. Negative Attitudes of Healthcare Providers towards Patients

"Nurses generally seem to be overworked and, consequently, exhausted. It is no wonder they are not always smiling." – Dr. Duze, Principal Medical Officer at Stanger Hospital⁷⁹

According to Dr. Duze, another consequence of the highly stressful, demanding and "often underappreciated⁸⁰" work of health care providers is negative attitudes from

⁷⁹ Dr. Duze, 06/11/06.

⁸⁰ Dr. Duze, 06/11/06..

some providers—particularly nurses-- towards their patients⁸¹. Throughout my experience living and studying in KZN, I have found widespread evidence of what Dr. Duze calls the “nurse-attitude problem⁸².” Epidemiologist Mark Colvin in his lecture to the SIT students stated that the attitudes of nurses have been a major issue within the public health system in KZN⁸³. In January of 2006, researchers at the Gender AIDS Forum (GAF), an activist Durban-based NGO, dove into the issue of nurse-attitudes in their study *Things are so wrong out there”: The experiences of women living with HIV & AIDS in accessing sexual and reproductive health & rights in KwaZulu Natal, South Africa: A study with women living with HIV and AIDS*. The researchers at GAF explained that the intent of the paper was to highlight women’s difficulties in accessing their reproductive and sexual rights within the public health care sector. The GAF researchers found that the “behavior of healthcare workers towards clients often undermining, rude and dismissive⁸⁴.” Some of the what they uncovered was shocking. One patient studied said, *if you are sick they shout at you and say that you are pretending. They tell you that you are not the only patient who is sick in the clinic ‘so keep quiet and stop making noise’*. Another women reported verbal abuse by a health care worker in a clinic where she went for treatment, *how are you feeling today—you look like granny*.

⁸¹ Dr. Duze, 06/11/06. A possible explanation to why nurses seem to have more negative attitudes than doctors is because, according to Dr. Duze, nurses often work longer hours and see more patients than doctors in a day. Furthermore, nurses get less money and are often less appreciated for their work.

⁸² Dr. Duze, 06/11/06.

⁸³ Dr. Colvin, 19/09/06.

⁸⁴ Barnabas L., Madlala N., Magwaza T., Maphumulo T., Mcanyana N, Mlambo R, Mpungose, G., Ngidi C., Tallis V. & Tolofi, R..“*Things are so wrong out there”: The experiences of women living with HIV & AIDS in accessing sexual and reproductive health & rights in KwaZulu Natal, South Africa: A study with women living with HIV and AIDS*. 24, January 2006.

While living with Ruby Makhathini, I witnessed another example of a negative healthcare provider -toward patient experience⁸⁵. When I arrived back to Ruby's home from class one day in September 2006, I noticed she was on the couch holding her hand in pain. I asked her what was wrong and she explained that after waiting in line for 5 hours at the clinic for her annual checkup, a nurse came to her with a needle, ready to take a shot. Ruby asked the nurse what the shot was for and the nurse replied to her *what are you a scared? Are you a child?* When Ruby explained to the nurse that she does not usually receive shots in her hand and asked why the nurse was about to give her the shot in this location the nurse snickered back *are you a doctor?* The nurse then jabbed Ruby's hand with the needle.⁸⁶ Her hand was completely swollen by the afternoon. Ruby then had to wake up the next morning again at 4:15 so that she would wait for hours at the hospital in order to alleviate the pain in her hand. That afternoon Ruby told me that the doctor at the hospital told her that she must go to the clinic superior and complain about the nurse's actions. As far as I know, Ruby never did. What is important to note about Ruby's experience is that she did not receive adequate information from the nurse about what the nurse was doing to her and was physically punished when she asked to receive information regarding the medical procedure about to be performed on her body.

It is hard to believe that the same off-putting attitudes of healthcare providers would miraculously change when it comes to pap smears. The GAF study found evidence that these negative healthcare worker attitudes had an affect on cervical cancer screening specifically. *You do not get comfortable when you are having a pap smear.*

⁸⁵ I lived with Ruby Makhathini from the period of 9/9/06 to 4/10/06. She is a 62-year old, Zulu woman living in a government subsidized home in Cato Manor, Durban, South Africa. She attends only public health sector facilities.

⁸⁶ As I was not at the clinic with Ruby, all the information presented about this experience was relayed to me by Ruby that afternoon. I did, however, witness the swelling of her hand when I returned from class.

One woman reported. *The nurse performed a pap smear on me in front of another sister, after me telling the sister that I don't want the other sister to stay.* Another woman described how *one nurse insisted on watching while the pap smear was done to a woman and as the woman left the nurse made a joke out of it.*

This provider-attitude problem seems to impinge significantly on clinic attendance in general⁸⁷. Of course, if a woman is avoiding the clinic system, it is highly unlikely she will be getting screened. And for those who are screened, such attitudes potentially discourage woman to come back for referrals or to uptake screening services again in the future. As GAF researchers conclude “because of [nurse-attitudes], women often avoid attending health care centers until they are desperate, so remain sick at home.”⁸⁸

Thus we see that the nurse attitude-problem could potentially be one reason why so many South African women have not been screened for cervical cancer and tend to only present at clinics when they already have late stage disease^{89, 90}.

iii. *A Cervical Cancer Screening Information-Dissemination Failure*

*Pap smears are performed on women without any information given about how or why it's done*⁹¹ - KZN clinic patient's comment to a GAF researcher

⁸⁷ Barnabas et al., 2006.

⁸⁸ Barnabas et al., 2006.

⁸⁹ Wellensiek et al, 2002.

⁹⁰ Not all sources agreed that there is widespread negative attitude and behavior of nurses. Dr. Warren explained to me that, in her experience, the really awful nurses were “in the minority” and that most have “so much love, go well beyond their work and are really amazing human beings who work under very stressful conditions in a remarkable way.” 23/11/06.

⁹¹ Barnabas et al., 2006.

Another possible consequence of the overworked, exhausting working conditions of the public sector healthcare workers is that such stress leads to a cervical screening information- dissemination failure from provider to patient⁹². In their 2002 study, Wellensiek et al. concluded that general education and specific knowledge concerning cervical screening are the *most important* factors to decide whether a screening policy will fail or succeed⁹³. Such a statement was corroborated by a report released by Reproductive Health Outlook, citing “poor communication between patients and health professionals” to be a major problem in developing countries’ cervical screening uptake and awareness⁹⁴. Several studies have demonstrated that the more information a woman knows about cervical cancer, the more likely she is to uptake screening services⁹⁵. And where is it that most women get their health-related information? *Their healthcare providers*.⁹⁶

I discovered a shocking example of a blatant healthcare provider information dissemination failure at Albert Luthuli. A middle-aged white woman came into the consultation room and sat down across from Dr Z.⁹⁷ The doctor began reading off her medical chart to her in an uninterested, monotone voice. Yet what she was telling the woman was far from banal. Using esoteric terms that the woman was unlikely to understand, she was attempting to inform the patient of a cancer diagnosis. The patient then interrupted the doctor and began saying that “the black and blue was fading on her

⁹² This alleged information-dissemination failure may not only be a consequence of overstrained working environments. It could also be a result of a lack of knowledge specific to cervical cancer on the part of the healthcare provider, a health care provider feeling of superiority over the patient or many other factors.

⁹³ Wellensiek et al., 2002.

⁹⁴ *Cervical Cancer Prevention: Key Issues*. Reproductive Health Outlook. (<http://www.rho.org>). 18/10/2006.

⁹⁵ Wellensiek et al., 2002.

⁹⁶ Dr G., 30/11/06.

⁹⁷ I will not use this patient’s name or the doctor’s name in order to protect their identities.

stomach” and asked the doctor, “what did they do to me in the operation?” The doctor responded that they removed her left and right ovaries, her uterus and her fallopian tubes. To my amazement the woman then asked, “why?” And the doctor responded, “because you had cancer, and now you must go to see if it has spread.” The woman was silent. This was the first time the patient found out that she had had her ovaries, uterus and fallopian tubes removed. And it was *after* the operation. It was also the first she had ever heard she had cancer and that it might have spread. It seems that no one before this doctor had properly explained her condition.⁹⁸

This story would likely come as little surprise to Wellensiek et al., who found that “health care workers in Durban often do not communicate adequately with patients.” While the problem seems to affect many aspects of health care, Wellensiek et al.’s work found evidence that was specific to cervical cancer. They discovered that while 27.3% of patients reported having had a Pap test, another 9.4% realized they had one in the past only after a speculum, a spatula and a glass slide were used for the purpose of demonstrating a Pap smear. Most of these women did not know the name and purpose of the test.⁹⁹ The GAF researchers also spoke to women who backed up the cervical cancer information-dissemination failure claim. One woman said that *pap smears are performed on women without any information given about how or why it’s done.*¹⁰⁰ Dr. Jordaan, too, said he would attribute part of the cervical cancer screening uptake problem to “slackness on the part of the medical profession to advocate strongly to patients about

⁹⁸ That this was the first time anyone had told the woman of her operation and cancer was confirmed by the doctor. Inkosi Albert Luthuli Hospital, *Observation*. 30/11/06.

⁹⁹ Wellensiek et al., 2002.

¹⁰⁰ Barnabas et al., 2006.

cervical cancer¹⁰¹.” And CANSA’s Joel Perry agreed, directly stating that “there is a failure in communicating this [cervical cancer] health information to women.”

At Albert Luthuli, Dr. G described how several of his patients were misinformed at their primary clinics before they were referred to him. He said that many patients with preinvasive lesions were told by their previous health care providers that the problem was a ‘sore’ in their womb. Women, he explained, do not take this information very seriously and “its possible that many do nothing about it.” At other times, he said, the providers tell the patients that they have full-blown cancer, when in reality they only have preinvasive lesions that will not develop into cancer if treated.¹⁰²

Studies have shown that “when people don’t know about pap smears, people don’t get screened¹⁰³” If many woman are not obtaining appropriate and sufficient information from their healthcare providers and such information has been closely linked to uptake of cervical screening programs, the 2000 cervical screening program may be partly failing because some healthcare providers are not disseminating information about cervical cancer to their patients.

3. Lack of Public Education on the Value and Purpose of Cervical Screening

“We never read or hear about cervical cancer screenings anymore”—Dr. Jordaan¹⁰⁴

¹⁰¹ Dr. Jordaan, 15/11/06.

¹⁰² Dr. G, 31/11/06.

¹⁰³ Dr. G, 30/11/06. This is an exact quote from Dr. G. It is corroborated in substance by Wellensiek et al., 2002.

¹⁰⁴ Dr. Jordaan, 15/11/06.

As detailed above it seems that implementation is failing partly because patients are not getting cervical cancer information. We have seen how there seems to be a failure of information specific to cervical cancer disseminated to patients from their providers. Yet there are other, critical places in which a woman could be accessing cervical screening information as she goes about her daily life. Here too is a possible reason for why the program is failing in implementation, as there is evidence of a scarcity of information about cervical cancer in the public sphere.

In 1998 the South African Institute of Medical Research organized infrastructure for mass screening in Soweto. The program had the resources available so that 90,000 women could get pap smears annually—the necessary screening infrastructure was there. Yet the program was deemed largely unsuccessful, as most women did not come to get screened. As the main reason for this failure the authors cited a “lack of planned population education and motivation program” to mobilize women to come get pap smears.¹⁰⁵ In another 2004 study, researchers found that 72% of South African public sector facilities that offered cervical screening services did not advertise them¹⁰⁶. Consequently, many women likely have no idea pap smears are available at their local clinics.

Many of my sources would not be surprised by the Soweto Projects failure or the lack of pap smear advertising carried out by facilities as they deem the lack of cervical cancer education and information to the public at large as a significant reason why the cervical screening program is failing to promote screening uptake. In the 2004 SAHR section about cervical cancer, the authors cited a “paucity of information, education and

¹⁰⁵ *Cervical Cancer Prevention*, RHO, 18/10/2006.

¹⁰⁶ Smit et al., 2004.

communication material regarding the importance of screening and implications of normal cytology,” as another one of the key challenges in translating the national policy into effective service¹⁰⁷. The Review recommended widespread dissemination of information pertaining to cervical cancer to communities in order to increase uptake. Dr. Roberts asserted that one of the biggest problems in cervical cancer screening uptake is that women are not educated at all about cervical cancer¹⁰⁸. Similarly, Dr. Warren stressed that one problem was that “[cervical cancer screening] is not advertised in our culture at all¹⁰⁹.” When I asked Dr. Jordaan what he thought some of the major challenges were in the uptake of the cervical screening program, he explained to me that *fifteen or twenty years ago there were big publicity campaigns about cervical cancer screening. It was in the newspaper, it was on the radio, in the clinics. But you never read or hear about cervical screening anymore*¹¹⁰.

If there are cervical cancer awareness efforts, they did not seem to be getting through to Ruby¹¹¹. When, I went to visit Ruby in November, I casually asked her if she had ever had a *pap smear*- with emphasis on the term. She looked at me as though I was speaking a different language—clearly unsure of the meaning of the term *pap smear*. I changed course and asked Ruby if she had had cervical cancer screening and she began to talk about her breast and what I soon realized was a mammogram—evidently thinking that I had asked her about breast cancer. Minutes later, she changed the subject to something

¹⁰⁷ Smit et al., 2004.

¹⁰⁸ Dr. Roberts, 21/11/06.

¹⁰⁹ Dr. Warren, 23/11/06.

¹¹⁰ Dr. Jordaan, 15/11/06.

¹¹¹ Ruby, 2/11/06. I went to visit Ruby in her home because it was her birthday. The two of us ate cake and drank tea and chatted for about an hour before I brought up the cervical cancer topic.

lighter and the conversation was over. These observations lead me to believe that it is unlikely any cervical cancer advocacy or education efforts had ever reached Ruby.

My limited observations in the clinics and throughout the community are also in line with what my sources assert. When waiting in the Oncology clinics of both Addington and Inkosi Albert Luthuli Hospitals, I immediately noticed the many colorful signs on the walls. In Addington there were five posters on the wall and *all five* advertised breast cancer awareness. At Albert Luthuli there were four posters and several pamphlets on a table. The posters advocated breast pumps, osteoporosis, breast feeding and healthy eating during pregnancy. The pamphlets discussed breast cancer and TB. In both these oncology clinics, there was not one visible poster or pamphlet in which a waiting woman could learn about cervical cancer—the leading cause of cancer deaths in South African women.¹¹² Furthermore, September 2006 was deemed Cervical Cancer Awareness month by the Department of Health. During this month, I lived in Cato Manor, a neighborhood in which the great majority of people use public sector facilities. In this time I walked throughout the neighborhood with my homestay brother¹¹³, went to the supermarket with a relative, visited the Cato Manor Community Center, and explored Durban. Yet I did not see, read, or hear anything about cervical cancer at all.

As Joel Perry explained, “there is a challenge to health and social organizations as a whole, to provide essential information to the public at large, in this case women in particular, to enable them to take charge of their health¹¹⁴.” As such, the apparent lack of cervical cancer education and awareness efforts in South Africa seem to be significantly

¹¹² Addington Hospital and Inkosi Albert Luthuli Central Hospital. *Observation*. 15/11/06 and 30/11/06 respectively.

¹¹³ My homestay brother is Bhuwa, Ruby’s 15 year old grandson who I shared a home with in Cato Manor.

¹¹⁴ Joel Perry, 27/11/06.

undermining any efforts to strategically implement the 2000 Cervical Cancer Screening Program.

PART TWO: A Problem of Context

Above I have discussed in detail possible explanations for why the 2000 National Guideline on Cervical Screening has not been comprehensively implemented in KwaZulu- Natal. I have described evidence that there is a resource-deficiency in some facilities of the public sector, detailed possible consequences of an overstrained health work force and provided evidence that the public-at- large is not receiving sufficient education about cervical screening. In this next part of my paper, I first describe the apparent rationale behind the 2000 Cervical Cancer Screening Program. I then argue that based on evidence I have come across, even if the screening policy is sufficiently and comprehensively implemented, cervical cancer will likely still be a significant problem in today's South Africa in general and KZN in particular because of the high prevalence of HIV. This is because HIV has been shown to 1) *decrease* the age at which women have cervical cancer and 2) *decrease* the interval of time from dysplasia to cancer and 3) *increase* the likelihood of false-negative results of pap smears.

The Rationale behind the Cervical Screening Program

The 2000 National Guideline on Cervical Screening Program is largely based a 1986 report by the International Agency for Research on Cancer (IARC), a department of

the WHO¹¹⁵. The policy guidelines are likely appropriate and effective for many low-resource settings throughout the world because of the nature of cervical cancer progression. The peak of HPV infection generally occurs between the ages of 16 and 20 years. Yet importantly, HPV infection *resolves spontaneously* in almost 90% of infected women. If a country were to screen and treat women when they begin to be sexually active, the great majority (80%) of women may show abnormalities, but most (90%) of these abnormalities will regress on their own¹¹⁶. Consequently, such a program would be squandering resources, as most women will clear infection and need not be screened and treated. But in some women HPV infection persists and precancerous cervical lesions may follow. If untreated, these lesions may progress to cancer, usually over a period of 10-20 years.¹¹⁷ Since high-grade dysplasia peaks at around age 35, but takes an average of 10 years to develop into cancer, it is therefore most realistic and effective in settings without the resources to repeat screening frequently over a wide age range to target the screening to older women (who have higher risk) in longer intervals (it takes around 10 years to develop cancer) with an emphasis on higher coverage of the targeted populations.¹¹⁸

The chart below, found in the National Guideline on Cervical Cancer Screening Program and based on WHO figures, shows the evidence the Department used when creating the cervical screening policy¹¹⁹.

Number of years between	Total smears per	Reduction in cumulative incidence of
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¹¹⁵ Smit et al., 2004.

¹¹⁶ Cervical Cancer Prevention, RHO, 18/10/2006

¹¹⁷ Preparing For the Introduction of HPV Vaccines, March 2006

¹¹⁸ Sankaranarayanan et al., 2001

¹¹⁹ *National Guideline on Cervical Cancer Screening Programme*, 2000.

Pap smears	lifetime	cervical cancer (%)
1	30	94
3	10	91
5	6	84
10	3	64

The Department of Health cited these figures as the reason for proposing their policy of 3 smears per lifetime, with a 10 year interval between each smear, commencing at no earlier than the age of 30 years.

Based on the above facts and figures, an *implemented* 2000 cervical screening policy would appear to be an effective strategy to reduce cost, incidence, and mortality of cervical cancer. Yet local data seems to demonstrate otherwise. Evidence I have found suggests that high-grade dysplasia and cervical cancer is a growing problem among *young* South African women. Dr. Jordaan described how in the past 26 years he has been working at Addington and in the last 36 years he has specialized in Oncology, *there has been a shift to much younger cervical cancer patients, and the shift has been major. Now more and more girls from ages 14 to 35 are coming in and needing treatment*¹²⁰.

Additionally, the 1998 cervical cancer screening project in Soweto, described above, found unexpectedly high rates of dysplasia among young teenagers¹²¹. Dr. Warren too noted that “very young girls in South Africa are coming in with cervical cancer¹²².” In fact, the Minister of Health herself in a speech commemorating Breast, Cervical and

¹²⁰ Dr. Jordaan, 15/11/06.

¹²¹ *Cervical Cancer Prevention. RHO, 18/10/2006.*

¹²² Dr. Warren, 23/11/06.

Prostate Cancer Month stated that researchers have shown that cervical cancer is the most common cancer among young South African women aged 15-19 years old¹²³.

In the late 80s and early 90s when the policy was being formulated, this may indeed have been the most effective cervical screening program¹²⁴. Yet, *within the context of KZN and South Africa today*, the above evidence suggests that these WHO guidelines may not be the most appropriate and effective model for a National Cervical Cancer Screening Program. There seems to be one main culprit: HIV/AIDS¹²⁵.

HIV and the Onset of Cervical Cancer

“The mean age of HIV-positive cervical cancer patients is about 13-15 years younger than that of their HIV-negative counterparts” - Dr. Manivasan Moodley¹²⁶

There is emerging evidence that HIV- positive women with invasive cervical cancer tend to be much younger than HIV-negative cervical cancer patients¹²⁷. A 2006 study conducted in London matched AIDS and cancer registries and found the average age for carcinoma in situ in HIV-infected women and HIV-negative women to be 32.7 and 47.5 respectively¹²⁸. Reproductive Health Outlook asserts on their frequently

¹²³ Speech by Minister Dr. Manto Tshabalala-Msimang at the community event in Mpumalanga to commemorate the Breast, Cervical and Prostate Cancer Month. 6/10/06.

¹²⁴ Dr. Manivasan Moodley, Department of Gynaecology Oncology, Nelson R. Mandela School of Medicine. *Interview*, 01/12/06.

¹²⁵ I must also add that some sources have also suggested that the young sexual debut of African women may lead to earlier HPV infection and consequently younger ages of cervical cancer as well. Smit et al., 2004.

¹²⁶ Dr. Moodley, 1/12/06.

¹²⁷ Dr. Moodley, 1/12/06.

¹²⁸ Danso, D., Lyons, F., Bradbeer C. *Cervical Screening and Management of cervical intraepithelial neoplasia in HIV positive women*. Int J STD AIDS. 2006 Sep;17(9):579-84.

updated website that HIV- positive women with invasive cervical cancer tend to be at least 10 years younger than HIV-negative cervical cancer patients¹²⁹. And Dr. Jordaan cited the reason for the aforementioned shift to younger girls getting cervical cancer was increased rates of HIV infection¹³⁰.

Between 2001 and 2006, Dr. Manivasan Moodley and his colleagues at the Obstetrics and Gynecology Department at the Nelson R. Mandela School of Medicine did research to see if they would find the same link between HIV and cervical cancer in one of the world's highest prevalence areas—KwaZulu-Natal. What they found was that the mean age of the HIV-positive cervical cancer patients that they studied was about 13-15 years younger than that of HIV-negative patients. Most of the HIV-positive subjects with cervical cancer were in the 30-40 year old age group, whereas the majority of cervical cancer subjects who were HIV- negative were in the 50-60 year old age group.¹³¹ There thus appears to be a significant association between the age at which women present with invasive cervical cancer and their HIV status.

HIV and the Interval of Time from Dysplasia to Cancer

“We have seen time and time again cervical cancer develop within as little as one year in our HIV infected patients.” - Dr. G¹³²

¹²⁹ Cervical Cancer Prevention, RHO, 18/10/2006.

¹³⁰ Dr. Jordaan, 15/11/06.

¹³¹ Dr. Moodley, 1/12/06. Interestingly, in these studies Dr. Moodley did not find evidence that cervical cancer was an AIDS-defining illness in patients with HIV, a link that has been accepted in the United States since 1993.

¹³² Dr. G, 30/11/06.

Well-documented evidence seems to suggest that women infected with HIV progress from HPV infection to cervical cancer much more rapidly. The 2006 London study described above found that the interval for developing invasive cervical disease is indeed shorter, with the average number of years between dysplasia and cancer 15.7 in HIV- negative woman and 3.2 in HIV- positive women¹³³. A 2003 study in Nairobi, Kenya found that young women with invasive cervical cancer were more often HIV infected and asserted that “these findings suggest an accelerated clinical progression of premalignant cervical lesions to invasive cervical cancer in HIV-infected women¹³⁴.” In Durban, a 2002 study also found that locally “HIV alters the natural history of HPV infection... with more rapid progression to high grade and invasive lesions¹³⁵.”

Furthermore, when talking to Dr. G, he explained that one of major reasons he disagreed with the cervical screening policy was the fact that women must wait 10 years between smears. “We have seen time and time again cervical cancer develop within as little as *one* year in our HIV infected patients, he explained, “a 10 year interval between tests is much too long¹³⁶.” And Dr. Moodley, too, confirmed that the literature has consistently shown that there is a more rapid progression from dysplasia to cancer in HIV positive women¹³⁷.

HIV and False-Negative Pap Smears

¹³³ Danso et al., 2006.

¹³⁴ Gichangi PB, Bwayo J, Estambale B, De Vuyst H, Ojwang S, Rogo K, Abwao H, Temmerman M, *Impact of HIV infection on invasive cervical cancer in Kenyan women*. AIDS. 2003 Sep 5;17(13):1963-8

¹³⁵ Clark B. & Chetty, R. *Postmodern cancer: the role of human immunodeficiency virus in uterine cervical cancer*. Molecular Pathology, 2002 Feb;55(1):19-24.

¹³⁶ Emphasis added. Dr. G, 30/11/06.

¹³⁷ Dr. Moodley, 2006.

“HIV-infected women were shown to have double the rate of false negative pap smears than HIV-negative women”- E Vazquez, 1999.¹³⁸

There is also evidence that HIV- positive women are more likely to receive false-negative pap smear results than HIV-negative women. In a 1999 study, 184 HIV-positive and HIV-negative women received a blood sample evaluation, Pap test, coloposcopy, and a directed biopsy¹³⁹. The false-negative rate among the HIV-positive women was found to be 37 percent, while the rate among HIV-negative women was 21.4 percent¹⁴⁰. Another 1999 study found that HIV-infected women were shown to have as high as double the rate of false negative pap smears as did HIV-negative women¹⁴¹. At the 14th International AIDS Conference in Barcelona in 2002, researchers reported that HIV-positive women are significantly more likely to have false negative pap smears and stressed that as such screening at shorter intervals may be warranted to increase the likelihood of a correct pap smear result¹⁴².

A Department of Health Inconsistency?

The above evidence that HIV-positive women are getting invasive cervical cancer at younger ages, with faster progression from dysplasia to cancer and an increased rate of false-negative pap smears is well-documented¹⁴³. If HIV- positive women are getting

¹³⁸ Vazquez E, *The danger of using only one pap smear*. Posit Aware. 1999 May-Jun;10(3):23.

¹³⁹ A directed biopsy is when a physician removes small pieces of cervical tissue from areas of the cervix where abnormal tissue has been detected.

¹⁴⁰ *False-negative Pap test rate high*. Newsline People AIDS Coalit N Y. 1999 Apr-May;;31

¹⁴¹ Vazquez, 1999.

¹⁴² Anderson J., Shah, K., Paramsothy, P., Heilis, C., Jamieson, D., Duen, A. *Predictive value of pap smear screening in HIV infected and high risk HIV uninfected women*. 14th International AIDS Conference, Barcelona, Spain. July 7-12, 2002.

¹⁴³ Dr. Moodley, 1/12/06.

invasive cervical cancer as young as 30, being screened for the first time at that age is untenable. If HIV-positive women are progressing from dysplasia to cancer in rates as short as 1-4 years, with a higher chance of false-negative smears, waiting 10 years between each smear is just too long. The evidence thus suggests that HIV-positive women should be screened for cervical cancer at younger ages, with shorter intervals between each smear.¹⁴⁴ Yet, the Guidelines for the National Cervical Cancer Screening Program states that “to date no association has been found between invasive cancer of the cervix and HIV infection¹⁴⁵” and therefore does not take the above evidence into account in its current *cervical screening* policy.

However, there is a noticeable incongruity within the department. *From HIV side*, the Department *does* seem to recognize an association between cervical cancer and HIV. In their most recent Guidelines for HIV/AIDS Clinical Care, the Department includes carcinoma of the cervix in a section entitled *HIV-related malignancies*. In another section that lists several AIDS-defining illnesses; invasive cervical cancer is included on the list. And most significantly, the guidelines emphasizes that “the pap smear must be regarded as a routine procedure in woman [HIV] patients and repeated *annually*.”¹⁴⁶ Moreover, the link between cervical cancer and HIV also seems to be recognized in the Department of Health ARV rollout program. When a woman comes to an ARV clinic and her CD4 count is under 200, she must get a pap smear from the clinic before she can receive treatment¹⁴⁷.

¹⁴⁴ The Center for Disease Control (CDC) in the United States recommends that HIV- positive women receive two pap smears at 6 month intervals within the first year of HIV diagnosis, followed by annual pap smear tests if those are normal.

¹⁴⁵ *National Guideline on Cervical Cancer Screening Programme*, 2000.

¹⁴⁶ Emphasis added. *HIV/AIDS Clinical Care Guidelines for Adults*: HIV/AIDS & STD Directorate, Department of Health, 2003.

¹⁴⁷ Mags Beksinska, 17/11/06.

There thus appears to be a discrepancy within the department regarding the association of cervical cancer and HIV. From the cervical cancer guidelines, the department denies any link between HIV/AIDS, but from the more recently updated HIV/AIDS guidelines, the link is recognized. As such, it is likely that some high-risk patients are indeed being screened at younger ages (when they present at clinics or ARV rollout sites) at more frequent intervals, as the evidence described above suggests is necessary.

A reasonable person might argue that as long as the department is recognizing and treating HIV-positive women differently with regards to cervical cancer, the screening guidelines should remain as they are—for older women at longer intervals-- since this has been recognized to be the most appropriate and effective program for a population of HIV-negative individuals. Yet as statistics illustrate, the extent and nature of the HIV/AIDS epidemic in KZN makes this sort of approach very troubling.

South Africa is approximated to have 10% of the globe's HIV-infection. The Burden of Disease Research Unit at the Medical Research Council (MRC) estimates that out of the nearly 48 million South Africans, 5.4 million are currently HIV-positive. Estimates indicate that about four women to everyone one man is infected with HIV for individuals aged 15 to 24 years old. The prevalence for women reaches a peak at ages 25-29 with 32.5% of the South African population infected with HIV. KwaZulu-Natal has the highest prevalence of HIV infection accounting for approximately 28.7% of all South African infections. It is estimated that around 40% of the antenatal population is

HIV- positive and in KZN the highest prevalence of the disease occurs in young women aged 20-29.¹⁴⁸

As can be seen, South Africa has one of the worst HIV/AIDS epidemics in the world, KZN has the highest prevalence in South Africa and women between 20 and 29 have the highest rates in KZN. And, significantly, there is evidence that many of these women *do not know their HIV status*¹⁴⁹. And those who do know their status must be part of the ARV rollout program, *and* have a CD4 count under 200, to be getting free smears. Consequently, though evidence points to the notion that HIV-positive women should be getting pap smears at younger ages and at more frequent intervals, *it appears very unlikely that many of these women are in fact doing so in KZN*. This is because the ARV rollout is still very slow, with the majority of people infected with HIV not yet accessing this program¹⁵⁰. It is because people with CD4 counts greater than 200 do not get pap smears at ARV clinics and must either wait until they turn 30 or until their CD4 counts drop to below 200 to get their first free smear.¹⁵¹ And lastly, because the thousands of positive women under 30 who do not yet know their HIV- status, but are at high-risk for cervical cancer, are not being screened at all.¹⁵²

If the Department of Health is serious about cervical cancer prevention, it seems as though it must update its policy to reflect the South African context described above. And my sources appear to agree. Dr. Jordaan described the policy as “very old

¹⁴⁸Dorrington, R., Johnson L., Bradshaw, D., Daniel, T. *The Demographic Impact of HIV/AIDS in South Africa*. National and Provincial Indicators for 2006. Cape Town: Center for Actuarial Research, South African Medical Research Council, and Actuarial Society of South Africa.

¹⁴⁹ This may be because of fear of stigmatization and abuse. Dr. Catherine Burns, Department of History at the University of KwaZulu-Natal. *Lecture, History of Health in South Africa*, 26/09/06.

¹⁵⁰ Mags Beksinka, 17/11/06.

¹⁵¹ Mags Beksinka, 17/11/06.

¹⁵² Women of course, can pay for pap smears if they are not within the target age group or want more than 3 smears, but as Dr. G stressed, those who are in the most need for screening are also the ones who cannot afford anything but free smears (31/11/06).

fashioned¹⁵³.” Dr. Warren complained that the *policy is completely flawed; women definitely need to be screened at younger ages*¹⁵⁴. Dr. G told me bluntly that he does not agree with government policy at all, mainly because “HIV patients need to be screened more frequently.¹⁵⁵ And Dr. Moodley asserted that the South African policy is “not going to work for HIV positive women” and as such, it is time to “relook at our screening policy.”¹⁵⁶ It seems that many relevant stakeholders are “fed up”¹⁵⁷ with the current guidelines and want change. Perhaps the 2004, SAHR said it best when it stated that “due to the prevalence of HIV in South Africa, health researchers and policy makers must consider the impact of HIV on the manifestation of cervical cancer and how this would relate to the minimum age and intervals between screening¹⁵⁸”.

¹⁵³ Dr. Jordaan, 15/11/06.

¹⁵⁴ Dr. Warren, 23/11/06.

¹⁵⁵ Dr. G, 30/11/06.

¹⁵⁶ Dr. Moodley, 1/12/06. It is important to note that the development of policy has often been slow. As Dr. Moodley explained, *the process here in Africa is very slow, it takes years for the many different stakeholders to formulate policy, and often when they finally do the policy is already outdated.*

¹⁵⁷ Dr G., 30/11/06.

¹⁵⁸ Smit et al., 2004.

Conclusions

Based on the limited evidence I have gathered through interviews with relevant stakeholders, through investigations of relevant documents and through general observations from studying and living in KwaZulu-Natal, I have found that it may be time for the Department of Health to reexamine its approach to cervical screening. The evidence I have detailed points to the notion that the current National Guideline of Cervical Screening Program does not appear to be comprehensively implemented and may not be suitable within the context of the HIV/AIDS epidemic. I have discussed in detail possible reasons for this failure of implementation suggesting that there are inadequate resources in the public sector, that overstrained healthcare workers cause pap smears to fall low on the list of health priorities, provider attitudes that discourage clinic attendance as well as a possible information-dissemination failure from healthcare provider to patient. I have also described evidence suggesting that there is inadequate publicity of the cervical screening program to the public- at- large.

In addition, I found data that indicates that even if implemented, the cervical screening policy may not be suitable within the context of KZN because such a

substantial portion of the young female population is infected with HIV. Studies have found that HIV seems to decrease the age at which women have cervical cancer, decrease the interval of time from dysplasia to cancer and increase the likelihood of false-negative results of pap smears. Though this evidence suggests that HIV-positive women should be getting pap smears at younger ages and at more frequent intervals, it appears very unlikely that many of these women are in fact doing so in KZN. This is because the ARV rollout is still very slow, because people with CD4 counts greater than 200 do not get pap smears at ARV clinics and must either wait until they turn 30 or until their CD4 counts drop to below 200 to get their first free smear and because the thousands of positive women under 30 who do not yet know their HIV- status are not being screened at all. When a third of women aged 25-29 have HIV; it seems as though a policy ought to be formulated that considers this context.¹⁵⁹

What I have not said

I want to make clear what I *have not* said throughout this piece. I have not said that the Department of Health policy has grossly missed the mark when it comes to cervical cancer. The Republic of South Africa is approaching only its 13 year of democracy and has inherited a largely unequal health system in need of major overhaul¹⁶⁰. The policies and laws that underwrite reproductive health laws in South Africa today are among the most progressive in the world in terms of the recognition they

¹⁵⁹ It is important to note that the department of health did not respond to questions about their 2000 National Guideline on Cervical Cancer Screening Program asked by e-mail and telephone.

¹⁶⁰ Dr Colvin, 19/09/06.

give to human rights, including sexual and reproductive rights¹⁶¹. And when the Department of Health formulated its cervical screening program it took into account the best available evidence to reduce cervical screening incidence, mortality and cost in low-resourced settings.

Furthermore, competing health needs, such as HIV/AIDS, have justifiably taken up much of the Departments attention. With many women dying of HIV/AIDS even before they develop cervical cancer¹⁶², it seems vital first and foremost to reduce the morbidity and mortality associated with AIDS. Yet importantly, as more and more women are living longer with HIV as the ARV rollout becomes more accessible¹⁶³, more and more women will need to be screened for cervical cancer at shorter intervals and younger ages¹⁶⁴.

What can be done?

In her recent¹⁶⁵ speech at the Mpumalanga community event to commemorate Breast, Cervical and Prostate Cancer Month, Health Minister Tshabalala-Msiman made a statement. After citing that cervical cancer is the leading cancer in South African women aged 15-19 and that in 2000, 3,424 South African females died of cervical cancer, she said to South African women, “I implore you good people to go for regular screenings so that we could help arrest this condition before it is too late.” If only the Minister

¹⁶¹ Cooper, D., Marroni, C., Orner, P., Moodley, J., Harries, J., Cullingwath L., Hoffman, M. *Ten Years of Reproductive Health Policy and Status*. Reproductive Health Matters 2002, 12 (24): 10-85.

¹⁶² Dr. Roberts, 21/11/06.

¹⁶³ Much of the work on the association between HIV and cervical cancer that has been done precedes the advent of ARVs. Evidence suggests that the consequences of HIV still negatively impacts the progression of cervical cancer in women with higher CD4 counts and consequently that HIV positive women must be screened at short intervals. Still, more research is needed. Danso et al., 2006.

¹⁶⁴ Danso et al., 2006.

¹⁶⁵ On 6 October, 2006.

understood why these “good people” are not able to go for regular screenings. If only she realized that the mere provision of cervical cancer screening does not seem sufficient to ensure successful uptake of cervical screening services. Screening has been provided through the South African public sector health facilities for many years, yet there has been a minimal impact on cervical cancer morbidity and mortality because of the limited screening of the population at risk¹⁶⁶. No matter what policy the Department formulates, evidence suggests that a comprehensive implementation strategy that is adequately planned and takes into account the capacity of the public health system is vital to its success¹⁶⁷.

In addition, the disproportionate number of women infected with HIV in South Africa, particularly in KZN, seems to warrant a cervical screening policy that takes into account the association of HIV and cervical cancer. As Dr. Moodley explained, *there are not many parts of the world where you get such a high HIV prevalence in combination with such a high cervical cancer prevalence*¹⁶⁸. In this unique context, the WHO recommendations may not be the most effective guidelines for cervical screening. And thus it may be time to reexamine the country’s Cervical Cancer Screening Program.

¹⁶⁶ Smit et al., 2004.

¹⁶⁷ Cooper et al., 2006.

¹⁶⁸ Dr. Moodley, 1/12/06.

Epilogue

The Future: Acetic Acid and the HPV Vaccine

It is vital to mention important new developments that could have a large affect on cervical cancer screening, incidence and mortality in the future. In November of 2005, researchers at the University of Cape Town found that washing the cervix with acetic acid could pick up pre-cancerous lesions as effectively as pap smears¹⁶⁹. This is a significant breakthrough because acetic acid—the main ingredient in vinegar-- could easily be applied in resource-poor settings as it does not involve expensive laboratory procedures. Studies have also shown that this approach can be implemented by mid-level personnel and does not need laboratory services or highly trained staff. Furthermore, screening and treatment, where necessary, can be done at a single visit. However, the

¹⁶⁹ In this procedure, if abnormal cells are present, they show as white lesions after the cervix is washed with acetic acid.

impact of this approach on cervical cancer incidence and mortality still needs to be researched.¹⁷⁰

Another exciting new development is the recent introduction of HPV vaccines against cervical cancer. On 8 of June 2006 the United States' Food and Drug Administration (FDA) approved of two vaccines targeting HPV types 16 and 18 which are responsible for 70% of cervical cancer cases worldwide. Results from large studies of the HPV vaccines, with about 2-5 years of follow-up, showed almost 100% protection against cervical cancer precursor lesions related to the vaccines genotypes. The vaccines are expected to prevent cervical cancer in 70% of HPV-naïve women they are administered to.¹⁷¹ Though the price of HPV vaccines for developing countries is still not known, the vaccine is currently doing its rounds through South Africa's Medical Control Council¹⁷² and according to Dr. Moodley, may be approved within 18 months with a negotiated price appropriate to the South African economy¹⁷³. These exciting new developments should be taken into account when a new cervical screening policy is developed.

¹⁷⁰ Preparing For the Introduction of HPV Vaccines, March 2006.

¹⁷¹ Preparing For the Introduction of HPV Vaccines, March 2006.

¹⁷² The MCC is the regulatory body that oversees regulation of medicine in South Africa.

¹⁷³ Dr. Moodley, 1/12/06.

Limitations of the Study

All studies have shortcomings and biases. In this section, I list potential limitations and biases in my study with the intention of providing a more holistic impression of the work I have done.

This study was an Independent Study Project (ISP), required by the School for International Training (SIT) Study Abroad: Public Health Program. I was in South Africa, collecting the data on an SIT Study Abroad Program which provided the composition of my visit by assigning me to specific homestays in specific places and providing specific lecturers to address specific Public Health related topics. It is important to note that SIT is a Western-based, liberal-leaning program with ‘first-world’ resources and values.

The selection of course speakers for the program was an important indicator of what aspects of Public Health would be emphasized and how I would finalize my topic choice for my ISP. The collection of speakers was heavily weighted on the researcher and NGO employee sector—providing some, but limited information from healthcare providers who know about the everyday stresses and challenges of working in the public healthcare system and no access to government officials involved in drafting and implementing policy. My study too weighed heavily on the researcher and NGO employee sector. I also interviewed many doctors, but my work falls short when it comes to input from nurses, who often do the brunt of the work in the public sector¹⁷⁴. Such researchers and NGOs are quite used to being critical of government and perhaps not as able to understand and articulate the difficulties of implementation. The doctors I spoke to too may have difficulty understanding the stresses of life as a nurse, as described throughout my study.

I must also mention that my study does not have any input or feedback from the South African Department of Health. I called and e-mailed the department multiple times asking questions about the 200 National Guideline on Cervical Cancer Screening Program. I received no response from the department.

Each source I observed and interviewed likely has predisposed biases because of the nature of their race, work and character. In addition, because they are talking to a 21-year old, white, American student, informants may have censored their statements. Potential predisposed and researcher-influenced biases of each source are described below.

¹⁷⁴ The reason why my study did not have access to public sector nurses is detailed below.

Ruby Makhathini- Ruby is a 62-year old Zulu woman who lives in a government subsidized home in Cato Manor, Durban, South Africa. It is important to note that as an older, arthritis-ridden Zulu woman living in a township, Ruby may be more prone to complain about the health system because she uses it so often and thus has more chances to have negative experiences with the system. Additionally, there are several differences between Ruby and myself that could potentially bias the conversation. For one, I am 21, the same age as Ruby's grandson, so Ruby may feel that I am young and say (or refrain from saying) certain things because of my age. Yet I am white, and Ruby grew up and lived most of her adult life in apartheid South Africa—potentially creating a racial bias in the data. Furthermore, I am American, a country which is often perceived to be able to do something about problems all over the world. Ruby may have detailed certain things to me because she believed that as an American I had the power to do something about it.

Manto Tshabalala-Msimang- I did not meet with the Minister, but instead read Dr. Tshabalala's speech commemorating Breast, Cervical and Prostate Cancer Months. Because the media and several SIT lecturers have condemned the Minister's work with regard to HIV/AIDS, I may have come with a preconceived notion that she is incompetent in her work when reading the words of her speech.

Mark Colvin- Mark Colvin sees the world from the lens of a white South African academic. He likely has never lived the day to day life of an impoverished person. He is also an epidemiologist, more inclined to look at statistics and trends in scientific data than he is to valuing anecdotal evidence. Furthermore, Dr. Colvin was speaking to a small classroom of *American* students and thus may have chosen what to speak about or stressed certain things because of the foreign background of his audience, possibly with the presumptions that Americans have the money and power to change things in South Africa.

Catherine Burns- Catherine Burns is a white South African historian. She, too, has likely never lived the day to day life of an impoverished person and may tend to emphasize historical trends to explain problems without focusing on present factors. Moreover, Catherine Burns was speaking to a small classroom of *American* students and may have chosen what to speak about or stressed certain things because of the foreign background of her audience.

Sister Thandanani Simelani- Significantly, Sister Simelani sees the world through the lens of a black South African educated woman. As an education-empowered nurse it is possible that she fails to grasp what an uneducated patient understands and knows about the health system. She also spoke to us at the end of her workday and was noticeably exhausted. In addition, Sister Simelani was lecturing in front of a group of 17 American, white students and may have consequently tailored how and what she spoke about and stressed because of the background and race of her audience—especially considering that Sister Simelani lived most of her adult life in apartheid South Africa.

Dr. Duze- It is important to note that Dr. Duze is an educated black doctor. He may feel superior to uneducated Africans from impoverished backgrounds and fail to relate to their problems. Furthermore, Dr. Duze was answering questions from a group of 17 American students and may have consequently stressed certain things in his answers because of the background of his audience. In addition 16/17 of these students were white and Dr. Duze lived most of his adult life in apartheid South Africa—potentially creating a racial bias in the data.

*Dr. Amo Jordaan—*Dr. Amo Jordaan is a white South African who has worked in Oncology department at Addington hospital through a period of historical change in South Africa. It is important to note that Dr. Jordaan works in the *public* sector and has chosen to work mainly in Gynecology. It is possible that he has chosen to remain in the public sector because he is liberal leaning and may believe in saving lives of those most in need. I could also be that the practical day to day work in the public sector has corrupted any romantic views of racial and socio-economic equality he may have had. It is also important to acknowledge that Dr. Jordaan spoke to me about the factors behind getting cervical cancer, which is a disease of females. As a white *male*, Dr. Jordaan has likely never lived in the conditions many of his cervical patients have had to live through. Also noteworthy is that Dr. Jordaan was speaking to me, a white, female, American student and may have stressed certain things because my gender, age or foreign background, possibly with the presumptions that Americans have the money and power to change things in South Africa.

Mags Beksinska- Mags Beksinska has moved to South Africa in her adult life and has Scandinavian roots. As an immigrant to South Africa, she might have less of a grasp for the historical changes with regard to reproductive health as someone her age who has lived here their whole life. She also likely has never lived the day to day life of many of the impoverished, ill people she researches and

likely does not herself attend public facilities. It is also important to note that Mags Beksinska was talking to a young, American student and may have stressed certain things because my age or foreign background.

Gender AIDS Forum (GAF)- Because it has liberal, feminist roots, GAF may tend to look at the AIDS with a bias toward women's needs without seeing the epidemic within the context of the larger public health sector system. Moreover, as an NGO, they likely have little experience with the challenges of policy implementation. As I searched through their resource room on my own, it is unlikely that there is a researcher-influenced bias here.

Charlie Roberts- As a white South African Doctor in the private sector, Dr. Roberts has likely never lived the day to day life of an impoverished person. In addition, as a private sector physician, he may not understand the challenges and stress-inducing conditions of work in the public sector facilities of South Africa. It is also important to note that Dr. Roberts was speaking to me about cervical cancer, a disease in which he, as a man, may not comprehensively understand. Furthermore, Dr. Roberts was speaking to me, a white, female, American student and may have stressed certain things because my gender, age or foreign background.

Paula Warren- Dr. Warren is a young, white doctor currently working in the private sector, who worked in the public sector last year. Because of her young age, Dr. Warren may tend to be more idealistic than the other, older doctors I spoke to. Furthermore, because she chose to leave the public sector, she may have certain negative memories of her experiences that potentially could have biased her answers to my questions. I mentioned to Dr. Warren that I was interested in becoming a doctor and she may have emphasized certain aspects of her job because she knew I was interested in the field. Furthermore, Dr. Warren may have stressed certain things because of my foreign background.

Joel Perry- Joel Perry is a white South African who is the Cancer Association of South Africa's (CANSA) Director of Health Programs. It is important to note that Joel Perry was speaking to me about cervical cancer, and as a man, he has no risk for this disease. Additionally, Joel Perry was speaking to me, a white, female, American student and may have stressed certain things because my gender, age or foreign background.

Dr. G.- As a black, male Gynecologist working at the Obstetrics and Gynecology Department of the Inkosi Albert Luthuli Hospital in Central Durban, Dr. G likely understands the cultural and social background of many of his patients, but as man has no risk for cervical cancer and has therefore never experienced the social consequences of contracting this disease. Also, as a highly educated man, he may feel superior to uneducated Africans from impoverished backgrounds and fail to relate to their problems. Furthermore, what Dr. G said to patients may have been biased by my presence in the consultation room. Even though he knew his identity would be hidden in my study, he may have said or stressed certain things to his patients because of the knowledge he was being observed by a young, white, foreigner. Also, he translated what he said to the patients into English from Zulu, with the understanding that I did not speak Zulu. There could potentially be a language barrier, and it is unlikely that the translation was exact.

Dr. Z.- Dr. Z is a black, female Oncologist working at Obstetrics and Gynecology Department at Inkosi Albert Luthuli Hospital in Central Durban. As an educated women, she may feel superior to uneducated Africans from impoverished backgrounds and fail to relate to their problems. Furthermore, what Dr. Z said to her patient may have been biased by my presence in the consultation room. Even though she knew her identity would be hidden in my study, she may have said or stressed certain things to her patient because of the knowledge she was being observed by a young, white, foreigner.

Manivasan Moodley- Dr. Manivasan Moodley is a doctor and researcher at Department of Obstetrics and Gynecology, Nelson R. Mandela School of Medicine. As a highly educated and well-respected academic, it is unlikely that Dr. Moodley lives the day to day impoverished lives of many of his patients. As my advisor, Dr. Moodley also had influence over who I spoke to and what I included in my work. I also knew that Dr. Moodley would be evaluating my paper, potentially biasing the contents of the study.

I must also acknowledge that many, though not all, of my secondary sources are academic papers published in International journals. As most International journals tend

to have a Western-bias, there may be such a bias in my secondary sources. In addition, the short list of articles that inform the study is by no means a comprehensive collection of the literature written on the topic.

Statistics constitute a large component of my study. As Benjamin Disraeli is so often quoted, “there are three kinds of lies: lies, damn lies, and statistics.” Of course, it is vital to acknowledge the inherent limitations in data collection and analysis and therefore stress that all statistics in this paper—whether obtained from primary or secondary sources-- should be eyed with caution, keeping in mind the inherent and researcher-influenced bias of the source.

It is critical to also acknowledge my own personal constructed identity as a white, American female who has been getting pap smears annually since the age of 16 *and has remained healthy*. Such a background may create partiality in my writing for innumerable reasons. My female identity may bias me to sympathize with the health needs of South African women, as I noticeably remembered more from lectures about women’s health. As an American, I have also been told that a woman is supposed to get a pap smear annually from the time she is sexually active or turns 18. Because of this policy, and my belief in its efficacy of preventing cervical cancer, I may have a tendency to be critical of another screening policy that is not my own. I also must recognize that the limited nature of this short research paper means that I do not have enough time to cover every side and argument to the issues presented.

It is also important to note that the study carried out was not the one I originally intended to study. This original project was based on evidence from Wellensiek et al.’s paper that a large problem with cervical cancer screening uptake in KZN is a failure of

communication from healthcare provider to patient. I intended to jump into this issue, by questioning healthcare providers in the public sector about how they perceive, screen and disseminate information about cervical cancer screening services within the context of the HIV/AIDS epidemic. I wanted to do this by providing a brief questionnaire to public sector healthcare providers. For the Proposal of the originally intended project proposal please see Appendix B. And to see the Questionnaire, please see Appendix C.

The reason why I did not carry out the project of my original intent was because of the many roadblocks in order to receive permission to submit my questionnaire to healthcare providers. I submitted by e-mail my Proposal, Ethics Approval and Questionnaire to Mr. Timothy Msiza, District Health Manager of KwaZulu-Natal. He said everything needed to be signed *and* I had to go to each clinic I intended to distribute my questionnaire and get their permission ahead of time. On the other side, these clinics said in order to come in, I needed Mr. Msiza's permission. Because this process was so time-consuming, I decided to change my project to an evaluation of the 2000 National Guideline on Cervical Cancer Screening Program by talking to relevant stakeholders, *without* submitting the questionnaire.

Recommendations for Further Study:

There are many avenues for further study discussed in this piece. Suggestions include:

- Research on the best strategy for implementation of a cervical cancer screening policy given the capacity of public health facilities throughout KZN and the rest of South Africa.
- Research on how the advent of ARVs may affect the association between HIV and cervical cancer.
- Further research on the interval of time from dysplasia to cervical cancer in HIV-positive patients specific to South Africa.
- Further research on the rate of false-negative pap smear results in HIV-positive patients specific to South Africa
- Research on the impact of the acetic acid screening approach on cervical cancer incidence and mortality.
- Research on how efficacy and safety of the HPV Vaccines in HIV infected individuals

-Research on the most strategic way to introduce the HPV Vaccines within the South African context.

-Research on how healthcare providers in Durban, South Africa Perceive, Screen and Disseminate Information about Cervical Cancer Screening Services within the Context of the HIV/AIDS epidemic (my original intention).

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Appendix A: Glossary of Terms

Carcinoma: Cancer that begins in the skin or in tissues that line or cover body organs. For example, carcinoma can arise in the breast, colon, liver, lung, prostate, and stomach.

Carcinoma in situ: Cancer that involves only the place in which it began and that has not spread. Carcinoma in situ is an early-stage tumor.

Cervical cancer: Cancer of the entrance to the womb (uterus). The cervix is the lower, narrow part of the uterus (womb). The uterus, a hollow, pear-shaped organ, is located in a woman's lower abdomen, between the bladder and the rectum. The cervix forms a canal that opens into the vagina, which leads to the outside of the body.

Regular pelvic exams and Pap testing can detect precancerous changes in the cervix. Precancerous changes in the cervix may be treated with cryosurgery, cauterization, or laser surgery. The most common symptom of cancer of the cervix is abnormal bleeding. Cancer of the cervix can be diagnosed using a Pap test or other procedures that sample the cervix tissue. Cancer of the cervix requires different treatment than cancer that begins in other parts of the uterus.

Cervix: The cervix is the lower, narrow part of the uterus (womb). The uterus, a hollow, pear-shaped organ, is located in a woman's lower abdomen, between the bladder and the rectum. The cervix forms a canal that opens into the vagina, which leads to the outside of the body.

Colposcopy : A procedure in which a gynecologist uses a lighted magnifying instrument which is called a colposcope to examine the tissues of the vagina and the cervix.

Dysplasia: Abnormal in form. From the Greek dys- (bad, disordered, abnormal) and plassein (to form). For example, retinal dysplasia is abnormal formation of the retina during embryonic development.

Human papillomavirus: HPV. A family of over 100 viruses including those which cause warts and are transmitted by contact. Some types of HPV are associated with tumors of the genital tract including, notably, cancer of the cervix.

Invasive cervical cancer: Cancer that has spread from the surface of the cervix to tissue deeper in the cervix or to other parts of the body.

Pap Smear: A screening test for cervical cancer based on the examination under the microscope of cells collected from the cervix, smeared on a slide and specially stained to reveal premalignant (before cancer) and malignant (cancer) changes as well as changes due to noncancerous conditions such as inflammation from infections.

Speculum: An instrument used to widen an opening to look within a passage or a cavity. For example, a speculum may be used to widen the opening of the vagina so that the cervix is more easily visible. Other examples include the nasal speculum to look up into the nostrils and the ear speculum to look within the ear canal at the ear drum. The term “speculum” is the Latin word for mirror.

Squamous cells: Flat cells that look like fish scales. The word “squamous” came from the Latin *squama* meaning “the scale of a fish or serpent.”

Squamous intraepithelial lesion (SIL): A general term for the abnormal growth of squamous cells on the surface of the cervix. The changes in the cells are described as low grade or high grade, depending on how much of the cervix is affected and how abnormal the cells are.

Appendix B: Original Project: Proposal

To Smear or Not to Smear?:

A Snapshot at How Health Care Providers in Durban, South Africa Perceive, Screen and Disseminate Information about Cervical Cancer Screening Services within the Context of the HIV/AIDS epidemic

Although it is a preventable disease that is curable if detected and treated in its early stages, cervical cancer remains the leading cause of cancer deaths among South African women. Women attending public sector services are entitled to three free Pap smears in their lives, yet the majority of eligible South African women have never had a Pap smear¹⁷⁵. In the HIV-burdened area of Durban in KwaZulu Natal, South Africa, cervical cancer poses an even greater threat as it is considered an AIDS defining illness in women affected with HIV¹⁷⁶. This project aims to get a snapshot of how different health care

¹⁷⁵ CANSA, Cancer Association of South Africa, *More services needed to fight cervical cancer* (www.givengain.com), 29/10/2006.

¹⁷⁶ *Cervical Cancer Prevention: Key Issues*. Reproductive Health Outlook. (<http://www.rho.org>). 18/10/2006.

providers in Durban perceive, screen and disseminate information about cervical cancer within the context of the HIV/AIDS epidemic. The study also aims to examine expert perceptions of the efficacy of the Republic of South Africa's cervical cancer screening policy. The project will interview public and private healthcare workers as well as experts in the field throughout the Durban area. Interviews will primarily take place at public health clinics in the greater Durban area as well as the Nelson R. Mandela School of Medicine.

While frequently repeated cytology screening have led to an 80% decline in cervical cancer mortality in developed countries, cervical cancer remains an important public health problem among adult women in the developing world. Due to more limited health care resources, developing countries cannot afford the model of frequently repeated screening of a wide age range of women that are used in developed countries. In such resource limited countries, the World Health Organization (WHO) supports the concept of reducing the number of smears per women per lifetime in favor of more women in the population having fewer smears¹⁷⁷. Yet even despite available screening facilities, the incidence of cervical cancer remains high with very few women being screened. And though most developing countries have registered either a stable or slowly declining trend in cervical cancer incidence, regions in sub-Saharan Africa have registered an increased incidence in recent years.¹⁷⁸

In South Africa, cervical cancer affects 1 in every 41 women¹⁷⁹. It is the leading cause of cancer deaths in South African women¹⁸⁰. And while the Department of Health's stated policy is that South African woman will receive 3 smears per lifetime with a 10 year interval between each smear, commencing at no earlier than age 30¹⁸¹, the majority of eligible South African women have never been screened for cervical cancer¹⁸².

Highly pertinent to South Africa, cervical cancer has been shown to be an important AIDS-related disease in women. Studies have shown that there is a higher prevalence of HPV infection in HIV positive women and that women with HIV have risk of more virulent HPV with more rapid progression from infection to neoplasia.¹⁸³ Evidence also suggests that HIV positive women with invasive cervical cancer are about ten years younger than their counterparts who are HIV negative. With 13.3% of South African women HIV positive¹⁸⁴, and with HIV/AIDS rates highest in KwaZulu-Natal, such cervical cancer-AIDS links are highly relevant. Current WHO screening recommendations are to screen HIV positive women every 6 months with a Pap smear

¹⁷⁷ *National Guideline on Cervical Cancer Screening Programme*. Republic of South Africa Department of Health, 1999.

¹⁷⁸ Sankaranarayanan et al.

¹⁷⁹ *National Guideline on Cervical Cancer Screening Programme*, 1999.

¹⁸⁰ Sankaranarayanan et al.

¹⁸¹ *National Guideline on Cervical Cancer Screening Programme*, 1999.

¹⁸² CANSA, Cancer Association of South Africa, *More services needed to fight cervical cancer* (www.givengain.com), 29/10/2006.

¹⁸³ *Cervical Cancer Prevention: Key Issues*, 18/10/2006.

¹⁸⁴ Ayesha BM Kharsany PhD, CAPRISA, University of KZN, South Africa, 30/10/2006. *Lecture: HIV Epidemiology and Prevention*

and refer for colposcopy any women who has atypia or dysplasia on her Pap smear¹⁸⁵. Yet the South African Department of Health Cervical Cancer Screening policy still asserts that there is no proven link between HIV and invasive cervical cancer¹⁸⁶.

Studies have shown that women in developing countries lack information on cervical cancer and know little about screening services available to them. Health care providers often have poor technical training in cervical cancer screening/treatment, education and counseling.¹⁸⁷ A 2002 study in Durban, South Africa that looked at knowledge of cervical cancer screening and use of cervical screening facilities of women from various socioeconomic backgrounds concluded that general education and specific knowledge concerning cervical screening are the most important factors to decide whether a screening policy will fail or succeed. The authors found evidence that “health care workers in Durban often do not communicate adequately with patients.” In support of this claim was the finding that while 27.3% of patients reported having had a Pap test, another 9.4% realized they had one in the past only after a Cusco speculum, a spatula and a glass slide were used for the purpose of demonstrating a Pap smear. Most of these women did not know the name and purpose of the test. Wellensiek et al. conclude that this was due to failure on the part of the healthcare giver to disseminate information to the patient regarding the reason and value of cervical screening.¹⁸⁸ Research on how different health care providers in Durban perceive, screen and disseminate information about cervical cancer within the context of the HIV/AIDS epidemic are crucial to the success of cervical cancer prevention programs. Such is the basis for my study.

By the end of the project I will have a limited snapshot of the perceptions that a small sector of Durban healthcare workers have on cervical cancer screenings and a greater understanding of some experts opinion on the Department of Health’s cervical cancer screening policy. I will also be able to observe the differences in health care worker knowledge, procedures and counseling to HIV positive versus HIV negative clients.

The majority of the data gathering will take place from the period of 13 November to 1 December, 2006. Some of the interviews will take place at public clinics with nurses who are in the facility on the given day that I provide a questionnaire to. I will also interview private sector healthcare providers. The interviews with academics will take place over the phone if a meeting cannot be set up or if the academic works in a different part of the country.

The interviews will be in the form of interviews/ guided conversations for academics¹⁸⁹ and questionnaires for health care providers.

Academics: The interviews with the academics will be more formal question and answer sessions as well as guided conversations. The overall goal is to understand the research

¹⁸⁵ *Cervical Cancer Prevention: Key Issues, 18/10/2006.*

¹⁸⁶ *National Guideline on Cervical Cancer Screening Programme, 1999.*

¹⁸⁷ CANSA, 29/10/2006.

¹⁸⁸ Wellensiek et al, 2002.

to date on cervical cancer perceptions, awareness and risk factors, its link to HIV/AIDS and to gain insight into the current challenges in the field.

Nurses/Doctors: The interviews with the nurses/doctors will be in the form of questionnaires. The questionnaire is attached below.

The budget for the project will be broken up as follows:

Accommodation/day: R50

Food/day: R50

Total Interview money: R15 x 15 people = R 225

Transportation/day: R50

Printing/Binding: R100(?)

I will be guided by Dr. Manivasan Moodley, Department of Gynaecology Oncology, Nelson R. Mandela School of Medicine. He can be reached at moodleym29@ukzn.ac.za or at 0824627518.

Appendix C: Original Questionnaire

Cervical Cancer Screening Questionnaire

1. At what age do you generally give your patients their first pap test?
2. What factors contribute to your decision to give a patient a pap test?
3. What do you tell a patient before and after you give them a pap test?

4. What do you tell a patient who is HIV positive about how often she should come for cervical cancer screening?

5. What proportion of women over the age of 40 visiting your clinic have never had a pap smear? (circle one)

All have had- Most have had- Half have had- Most haven't had- Virtually none have had

6. What do you see as the biggest challenge with cervical cancer screening in South Africa today?

Appendix D: National Guideline of Cervical Cancer Screening Programme

