AN EVALUATION OF THE CERVICAL SCREENING PROGRAMME IN JOHANNESBURG METRO DISTRICT, GAUTENG PROVINCE

Waasila Jassat

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfilment of the requirements for the degree of Master of Medicine in the branch of Community Health

Johannesburg, 2010

DECLARATION

I, Waasila Jassat, declare that this research report is my own work. It is being submitted for the degree of Master of Medicine in the branch of Community Health, in the University of Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Waasila Jassat

On the 28th day of October 2010

This work is dedicated to my family for their unstinting support and loyalty,

and especially to my son Aadam,

for his patience and humour throughout the research process.

PRESENTATIONS ARISING FROM THIS STUDY

1. Jassat W. **An Evaluation of the Cervical Screening Programme in Jhb Metro District, Gauteng Province.** Oral presentation. City of Johannesburg DHIS and Research Day. Florida, 25th March 2009.

2. Jassat W. **Evaluating the Cervical Screening Programme in Johannesburg Metro District: Recommendations for Improved Service Delivery.** Oral presentation. 12th Annual Gauteng Department of Health Prakash Vallabh Primary Health Care Research Conference. Session: Maternal Child and Women's Health. Krugersdorp, 1st September 2009.

3. Jassat W. **Evaluating Cervical Screening in the Johannesburg Metro District: Recommendations for Improving the Programme**. Oral presentation. 5th Public Health Association of South Africa (PHASA) Conference. Session: Sexual and Reproductive Health. Durban, 1st December 2009.

4. Jassat W. **An Evaluation of the Cervical Screening Programme in Johannesburg, South Africa**. Oral presentation. 12th World Congress on Public Health. Session: Poverty, Health and Development: Achieving the Millennium Development Goals (III). Istanbul, 30th April 2009.

ABSTRACT

INTRODUCTION: Cervical cancer continues to be a significant cause of morbidity and mortality, particularly in women in the developing world, due to the lack of effective population screening. It has proven difficult to implement and sustain cytological screening programmes as health systems in these settings are not functional. South Africa has adopted an organised cervical screening programme, and the goal is to screen 70% of women over 30 years nationally, within ten years of initiating the programme. However, it is also necessary to ensure that women with abnormal Pap smears are treated if we are to reduce cervical cancer incidence. Ensuring treatment of abnormal Pap smears is a challenge, and current data on this is needed to inform service delivery.

AIM: The study aims to assess the current status of the cervical screening programme in the Johannesburg Metro District, specifically looking at screening coverage, and referral for treatment in women with abnormal Pap smears.

METHODOLOGY: Secondary analysis of data in the District Health Information System was done; and registers at a sample of primary health care clinics and their referral colposcopy services were evaluated for the period April 2007 – March 2008. Descriptive statistics were employed to analyse the data. Multivariate analysis was also done to evaluate factors associated with colposcopy attendance.

RESULTS: Screening coverage for the district was 6.3% for 2008 and the cumulative coverage from 2000 to 2008 was 35.8%, with significant variation between sub-districts. A high proportion (19%) of smears was done in women less than 30 years.

Of 557 women with abnormal Pap smears requiring further treatment, 57% were informed of their results and referred, 38% had appointments for colposcopy, and only 28% attended these appointments. Women experienced long waiting times for appointments (up to 15 months), and there was inadequate record keeping and client tracing. HIV status and the sub-district and health authority where women were screened were associated with colposcopy attendance; the referral hospital was associated with length of waiting time between Pap smear and colposcopy.

CONCLUSION: Cervical screening coverage is below target, and the referral for diagnosis and treatment remains a challenge. Unless referral and access to colposcopy services is improved, increasing screening coverage will not have an impact on decreasing cervical cancer incidence and mortality. It is hoped that this study will provide the data to target interventions to improve cervical screening coverage and effective referral and treatment in the district.

ACKNOWLEDGEMENTS

First and foremost, I would like to extend my gratitude to my supervisor and academic mentor, Dr Mary Kawonga for her insight and good advice in all aspects of this research project.

I am grateful to Mrs Zareena Saloojee, acting Director of the Johannesburg Metro District, who helped and supported me in getting this project off the ground.

I would like to acknowledge the facility managers and staff members who assisted in sourcing information at the clinics. I am also thankful to sub-district and district managers who made it possible for me to visit the facilities.

I thank Mr Vusi Mbewu and Ms Andy Valashiya for their assistance in sourcing data from the District Health Information System (DHIS), and Dr Pamela Michelow for data accessed from the National Health Laboratory Service (NHLS).

I would also like to acknowledge a research grant I received to conduct this study, from the Faculty of Health Sciences, University of Witwatersrand.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

GLOSSARY

Coverage: The proportion of women in the target age group who are screened at the recommended intervals during a given time period.

Cervical Intraepithelial Neoplasia (CIN): A precancerous condition involving the covering layer (epithelium) of the cervix. The condition is graded as CIN 1, 2 or 3, according to the thickness of the abnormal epithelium (1/3, 2/3 or the entire thickness)

High-grade lesion: A term used in the Bethesda classification to denote cervical abnormalities that have a high likelihood of progressing to cancer if not treated. Includes CIN 2 and CIN 3

Screen-negative: Result of a screening procedure that shows no abnormality.

Screen-positive: Result of a screening procedure that shows an abnormality

Squamous intraepithelial lesion (SIL): Pre-cancer or abnormality of the squamous cells of the lining of the cervix. The Bethesda classification distinguishes between low-grade SIL (LSIL) and high-grade SIL (HSIL).

Referral: Physical referral of women to a clinical facility as a consequence of the screening test for diagnostic confirmation, e.g. by histology.

Screen and treat: A procedure where testing, confirmation and treatment take place during the same episode.

Screening interval: Fixed interval between routine screenings decided upon in each programme, depending on screening policy.

Screening policy: Specific policy of a screening programme which dictates the targeted age group, the geographical area, the screening interval, etc. Opportunistic systems may also have policies.

Target population: The population eligible for screening, i.e. all women recommended undergoing screening according to the policy adopted.

ABBREVIATIONS AND ACRONYMS

AGUS atypical glandular cells of unknown significance

AIDS acquired immunodeficiency syndrome

ART antiretroviral therapy

ASC-H atypical squamous cells: cannot exclude a high-grade squamous intra-epithelial lesion

ASC-US atypical squamous cells of undetermined significance

ASR age-standardised incidence rate

CHBH Chris Hani Baragwanath Hospital

CHC community health centre

CHW community health worker

CIN cervical intraepithelial neoplasia

CMJAH Charlotte Maxeke Johannesburg Academic Hospital

DHIS District Health Information System

EH Edenvale Hospital

HGL high grade lesions

HIV human immunodeficiency virus

HPV human papillomavirus

HSIL high-grade squamous intraepithelial lesion

IARC International Agency for Cancer Research

JMD Johannesburg Metro District

LBC Liquid-based cytology

LG local government

LSIL low-grade squamous intraepithelial lesion

NCR National Cancer Registry

NGO non-governmental organisations

NHLS National Health Laboratory Service

PHC primary health care

RMH Raheema Moosa Hospital

SIL squamous intraepithelial lesion

Stats SA Statistics South Africa

VIA visual inspection with acetic acid

VILI visual inspection with Lugol's iodine

WHO World Health Organization

CHAPTER ONE

1. INTRODUCTION

1.1 Background

Cervical cancer continues to be a cause of significant morbidity and mortality in women, particularly in the developing world.[1] Globally, it is the second most commonly diagnosed cancer and is the third leading cause of cancer deaths in women.[2] In South Africa, it remains one of the top two most commonly reported cancers in females, comprising 16.2% of all cancers in this group.[3] Cervical cancer is an even greater concern in South Africa due to the high prevalence of Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS), with which it is known to be associated.[4]

Without urgent action, deaths due to cervical cancer are projected to rise by almost 25% over the next 10 years.[5] These deaths could be prevented if the disease is detected early. The slow progression from mild dysplasia to carcinoma makes cervical cancer a feasibly preventable disease and provides the rationale for screening. There are various methods of screening but cytology is recommended for large-scale cervical cancer screening programmes, where sufficient resources exist.[1]

Screening for cervical cancer by means of Papanicolaou (Pap) smear became part of the package of care offered free of charge to all women in South Africa in 1996, and in 2001, a national cervical screening programme was launched.[6] According to the national policy, every asymptomatic woman aged 30 years or older will be screened three times in succession at ten year intervals, utilising cervical Pap smears.[6] The

objectives of the programme, as expressed in the national guidelines, are to reduce the incidence, 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.[6]

1.2 Statement of the Problem

In many developing countries where the burden of disease is highest, access to health services is limited and screening for cervical cancer either does not exist or does not reach the majority of women who need it.[5] It has proven difficult to implement and sustain effective population screening programmes in low-resource settings.[7] South Africa has a cytological screening programme in place but many challenges exist in implementing the screening programme.[8-10] A lack of political will, adequate financial resources and trained staff, effective referral mechanisms and laboratory facilities, and a health care infrastructure for diagnosis and treatment, along with many competing healthcare priorities, have hampered the organisation of effective cytological screening programmes in resource-poor countries, including South Africa.[11]

A successful cervical cancer control programme requires a high coverage rate above 80%, but this has not been achieved in South Africa.[9] Also, women with identified abnormalities should attend for diagnosis, management and follow-up but studies have shown that many women who have precancerous or cancerous lesions on Pap smears are often not referred to colposcopy services for diagnosis and treatment.[8,12,13] If women with abnormal smears are not referred and treated, all attempts to increase

coverage would be ineffective in decreasing the incidence and mortality of invasive cervical cancer, which is the ultimate goal of the programme.

This study aims to evaluate the cervical screening programme in the Johannesburg Metro District (JMD), a densely-concentrated urban metropolis in the Gauteng Province. An evaluation of the programme will be done using a health services research and evaluation approach. This will evaluate progress thus far regarding screening coverage and other programme output indicators. The study will also evaluate referral and treatment services to determine the programme's effectiveness and performance in referral of women with high-grade lesions.

1.3 Justification for the Study

The South African national cervical screening programme is approaching the ten year mark since its inception in 2000. This is a milestone because a goal of the programme was to have screened 70% of the target population by 2010.[6] It is therefore important to evaluate the programme at this point in order to measure the progress attained towards reaching those goals.

The World Health Organization (WHO) recommends that middle-income developing countries with inefficient cytology screening programmes should focus their attention on reorganising their programmes considering lessons from their past failures and experiences from elsewhere.[5] Many local studies have documented challenges experienced in different aspects of the screening service, and the resulting impacts on screening coverage, quality of Pap smears and effectiveness of referral

mechanisms.[8,13,14] However, there has not been a systematic evaluation of the South African national cervical screening programme, and evidence especially at district level of output indicators for the current screening programme is limited.

In order to reorganise the screening programme at district level, it is important to understand the specific challenges and barriers to successful implementation screening in the local context. Therefore, good data from Johannesburg Metro District and the Gauteng Province is necessary in order to inform improvements to the programme in this setting. This study hopes to provide much-needed information for district and provincial managers to inform further recommendations to improve cervical screening coverage and effective referral and treatment in the district.

1.4 Literature Review

1.4.1. Burden of disease

Despite being highly preventable and curable, cancer of the cervix remains a significant health problem, particularly in developing countries.[1,14] One in ten cancers reported worldwide are cancers of the cervix, and it remains the most commonly diagnosed female cancer in sub-Saharan Africa, South and Central America and south and south-east Asia.[15,16] Globally, over 85% of the nearly 560 000 new cases and the 309 000 deaths annually, occur in the developing world.[2] While incidence is declining in most developed and some developing countries due to effective screening programmes, the total burden of cervical cancer is rising in high-risk developing countries in sub-Saharan Africa. There is a seven-fold variation in incidence and

seventeen-fold variation in mortality from cervical cancer between developed and developing regions of the world.[1]

Cervical cancer is a relatively common disease in South Africa.[17] According to National Cancer Registry (NCR) reports, cervical cancer consistently remains one of the top two most common cancers in South African women.[3,18] A total of 4 817 cervical cancer cases were reported to the NCR in 2001, comprising 16.2% of all cancer cases reported in females in that year.[3] The age-standardised incidence rate (ASR) of cervical cancer was 26 per 100 000 women. ASR increased with increasing age, with 81% of cases occurring in women between 30 and 69 years, and incidence peaking between the ages of 60 and 64 years. ASR in White females was significantly lower (32 per 100 000) than in Black females (122 per 100 000). There is a disproportionate burden of the disease in Black women, who have a 1 in 29 lifetime risk of developing the disease, probably reflecting the differential exposure to risk factors and access to health screening services.

1.4.2. Natural history of disease and risk factors

Invasive cervical cancer develops from dysplastic precursor lesions, progressing steadily from low-grade to high-grade lesions, and finally to cancer.[5]

The primary underlying cause of cervical cancer is infection with high-risk human papillomavirus (HPV) types.[19] Most HPV infections resolve spontaneously; those that persist may lead to the development of pre-cancer and cancer. It usually takes 10 to 20 years for precursor lesions caused by HPV to develop into invasive cancer.

The key determinants of HPV infection for both men and women are related to sexual behaviour including early onset of sexual activity, multiple sexual partners and unprotected intercourse.[5] Additional co-factors are active and passive exposure to cigarette smoke, long use of oral and injectable contraceptives and immunosuppression.[5,20]

HIV and cervical cancer

Cervical cancer was classified an AIDS-defining disease in 1993,[21] and it has since been observed to be the most common AIDS-related cancer in women in Africa.[22] Studies have shown that HIV positive women have a higher prevalence of HPV infection with multiple high-risk HPV types, and are at a greater risk of developing cervical squamous intraepithelial lesions (SIL) and cervical cancer.[23-25] Several studies have reported the prevalence of SILs in HIV positive women to be 31% to 63%.[24,25] Evidence has shown that cervical lesions in HIV positive women tend to appear up to ten years earlier than in HIV negative women, progress more rapidly and are associated with higher mortality.[5,26] An increase in pre-cancerous cervical lesions with increasing HIV prevalence has been documented in many settings, including South Africa.[27] A case-control study of cancers in Johannesburg hospitals from 1995-2004, showed HIV positive women had 1.6 times higher risk of developing cervical cancer than HIV negative women.[28] A strong association between immune status (CD4 and viral load) and cervical abnormalities has been demonstrated.[29-31]

South Africa has the largest, expanding HIV burden in the world. It is estimated that 5.7 million South Africans are currently living with HIV/AIDS, 60% of them women.[32] In 2008, the adult prevalence in the age group 15-49 years was estimated at

16.9% [33] while the latest antenatal seroprevalence was 28%.[34] Considering the high prevalence of HIV especially in young women and the association with cervical cancer, the potential impact on disease burden deserves even greater scrutiny. The absence of an increased trend in cervical cancer incidence in recent years [3] is attributed to high competing mortality and deaths from other causes.[35] Increasing access to antiretroviral therapy (ART), however, may result in increasing life expectancy, which in turn may lead to a higher cumulative risk of developing cervical cancer.[25] Some have argued for a possible re-examination of criteria being used for cervical cancer screening in high HIV prevalence countries where the prevalence of cervical cancer is also high and access to antiretroviral treatment remains limited.[27]

1.4.3. Cervical cancer prevention

Cervical cancer is highly preventable either through primary prevention of exposure to risk factors, or through secondary prevention which is early detection and treatment of precancerous lesions through cervical screening.

Primary prevention involves prevention of HPV infection and cofactors known to increase the risk of cervical cancer, and includes education and awareness-raising to reduce high-risk sexual behaviours; provision of the HPV vaccine; and efforts to discourage tobacco use, including smoking.[5]

There is currently no available evidence on the effectiveness of behaviour change intervention, such as advising abstinence, delaying first intercourse, having fewer sexual partners, and using condoms, in reducing cervical cancer disease burden.

HPV vaccines: Recently developed candidate HPV vaccines designed to protect against infections with high risk HPV 16 and HPV 18 have shown promising results in clinical trials.[5] However, there are some programmatic concerns that still need to be addressed particularly in developing countries for these vaccines to be effective at population-level. For example, the vaccine should be equitably distributed in order to attain high coverage of adolescents before they become sexually active.[5] Also, acceptable coverage of young people is best achieved through a functional school-based public health system, which is not yet well established in South Africa.[9] Any impact of the vaccine on the incidence of cervical cancer would not be detectable for some decades after its introduction. Even after an HPV vaccine programme is fully implemented, there would still be a need for widespread cervical screening to continue.[4,5]

Secondary prevention stops the progression of pre-cancerous disease once it has already started. The natural history of cervical cancer, with its usually slow progression from early pre-cancer to invasive disease, provides the rationale for screening.[5] The objective of cervical screening is to prevent invasive cervical cancer by detecting and treating women with cervical cancer precursor lesions. Screening tests such as cervical cytology, visual tests, and HPV testing may all be used to identify precursor lesions. Regardless of the test used, the key to an effective programme is to reach the largest proportion of women at risk with quality screening and treatment of precursor lesions.[5]

Cytological screening: Cytological testing involves collection of exfoliated cells from the cervix using a spatula or brush, and microscopic examination of these cells after

staining. In South Africa, women with low-grade lesions are generally advised to return for routine follow-up smears. Women with high-grade precursor lesions are further evaluated via colposcopy, biopsy, and subsequent treatment of confirmed lesions.

Cytological screening requires a laboratory infrastructure; trained cytotechnologists and pathologists for processing slides and reporting; internal and external quality control; and a system for communicating the results to the women. It is also necessary for all women with high grade lesions on Pap smear to be referred for colposcopic diagnosis and management. The notification of results to women, as well as the three visits (one each for testing, diagnosis, and treatment) required for cytological screening, pose major programmatic and logistic challenges.[11] Despite this, the Pap smear is the only test that has been used in large populations and that has been shown to reduce cervical cancer incidence and mortality.[4,5] It is therefore still the recommended method of choice for cervical screening.

Liquid-based cytology (LBC): LBC is more expensive than conventional cytology and laboratory staff needs to be specially trained.[5] However, it appears to have a number of advantages over conventional methods: there are fewer false negatives; fewer unsatisfactory specimens; each specimen requires a shorter interpretation time; and the material collected can also be tested for HPV DNA.[5] The high cost however, makes it suitable for use only in settings where resources permit.

Visual methods: Two visual methods are available, viz. visual inspection with acetic acid (VIA) and visual inspection with Lugol's iodine (VILI). VIA and VILI are

promising alternatives to cytology where resources are limited because they do not rely on laboratory services, require a very low level of infrastructure, can be performed by a wide range of health personnel after a short period of training (1–3 weeks), are inexpensive, safe and acceptable techniques, and results are available immediately, eliminating the need for multiple visits in most cases, thus reducing loss to follow-up.[5]

However, high rates of overtreatment may result, given their relatively low test specificity. Visual inspection methods are subjective and present challenges to maintain the quality of testing. There is also no permanent record of the test that can be reviewed later. Therefore, visual screening methods, at this time, are recommended for use only in pilot projects or other closely monitored settings.[4,5]

HPV DNA-based screening methods: The HPV DNA test is simple to perform and has an increased screening sensitivity when combined with cytology, but requires a second clinic visit and costly laboratory infrastructure, making it unaffordable for low resource settings.[4,5] Detection of high-risk HPV does not necessarily mean that pre-cancer or cancer is present; it indicates simply that there is an HPV infection. Using HPV testing for screening would lead to a large proportion of women being told that they harbour a sexually transmitted viral infection that can ultimately cause cancer.[5] HPV DNA tests as primary screening methods, at this time, are recommended for use only in pilot projects or other closely monitored settings.[4,5] They can be used in conjunction with cytology or other screening tests, where sufficient resources exist.

The "screen-and-treat" approach: If there is no capacity for colposcopy services, treatment based on screening alone may be appropriate, especially in limited-resource settings. Screening tests for the screen-and-treat approach can include visual tests, HPV or cytological tests. With screening tests that provide immediate results, such as VIA and VILI, screening and treatment can be provided during a single hospital visit, thus reducing the screening programme's susceptibility to loss to follow-up.[5,36] In recent South African studies, one-visit strategies with visual inspection methods were demonstrated to be safe, more cost-effective, requiring only one visit, and were able to be performed by mid-level nurses in primary care settings, but would result in some overtreatment.[37,38] However, they had a lower specificity and positive predictive value, and are associated with over-referral to colposcopy and significant overtreatment.[39] Until these methods are proven in settings other than experimental ones, cytological screening remains the standard for application in low- and middle-income countries, and the alternative screening tests are still seen as complementary to cytology rather than competitive.[40]

1.4.4. Cytological cervical screening programmes

Much experience and evidence-based knowledge is available on the use of cytological screening in both developed and developing countries.[4,5] High quality cytology is a highly specific screening test, with estimates of the order of 98-99% and moderate sensitivity as high as 75%.[5] Well-organised cervical cytological screening programmes, involving screening of sexually active women annually or every 2-5 years, have been effective in reducing the incidence of and mortality from the disease in developed countries in the last 40-50 years.[5,41] In areas with high-quality screening, high coverage, and reliable follow-up of women, cytological screening has reduced

cervical cancer rates by 60% to 90% within three years of introduction to populations that had not previously been screened.[5,7] Even in countries where screening programmes are not ideally functioning, population-based screening programmes- either organised or opportunistic- have decreased the incidence of and mortality from cervical cancer in large parts of the world.[42,43] In South Africa, a study has shown that even limited Pap smear screening reduced the risk of cervical cancer.[44]

An analysis of trends in cervical mortality in South Africa from 1949 to 1990 revealed a consistent decline in deaths in White women from the 1960s after screening was introduced, while increased mortality was recorded in Coloured women.[45] This provides circumstantial evidence that screening had an impact on cervical cancer mortality in White women, while the increase in mortality seen in the Coloured population in that time reflects the inequitable distribution of and access to these services.

The high incidence and mortality of the disease in developing countries has been attributed to the lack of effective cervical screening programmes. The limited health care budgets in these settings do not allow initiation and sustaining of comprehensive programmes that involve substantial costs for the associated infrastructure, manpower, consumables, follow-up, and surveillance.[7] Other reasons why screening has not been implemented in developing countries include:

- lack of priority for women's sexual and reproductive health
- lack of national policies and appropriate guidelines
- lack of awareness of cervical cancer among the population, health care providers and policy-makers

- limited access to health care services
- lack of functional referral systems

In resource-poor settings, the WHO supports the concept of achieving wider coverage rather than more frequent screening.[5] This is because increasing coverage has the potential to reduce disease incidence far more than using a slightly more sensitive screening test or decreasing screening intervals.[46] The WHO advises that countries should focus on screening women between the ages of 30 and 49 years at least once in their lifetime, gradually expanding the programme to other age groups and then to more frequent screening. The WHO further recommends that existing organised programmes should not include women less than 25 years of age in their target populations as there is minimal benefit and substantial harm in screening below age 25; and screening is not recommended for women over 65 years, provided the last two previous smears were negative. Annual screening is not recommended at any age by WHO.[5] Many national programmes are moving towards decreasing the frequency of smears (once every 3-5 years) due to the slowly progressing nature of these lesions.[7]

Organised cytological screening is designed to reach the highest possible number of women at greatest risk of cervical cancer. It is usually planned at the national or regional level. Opportunistic screening is screening done independently of an organised or population-based programme, on women who are visiting health services for other reasons. This form of screening tends to reach younger women at lower risk, who are attending antenatal, child health and family planning services. Organised screening programmes designed and managed at the central level are preferable to opportunistic screening, as they are more cost-effective, and make better use of

available resources while ensuring that the greatest number of women will benefit. However, both organised and opportunistic screening can fail because of poor quality-control, low coverage of the population at risk, over-screening of low-risk populations, and high loss to follow-up.

Success of a population based cytological cervical screening programme is dependent on a number of critical factors:[47]

- Client recruitment: creating demand for screening services by educating communities and recruiting women in health facilities
- Screening service: providing screening services and ensuring high coverage (80%) of the population at risk; and good Pap smear quality
- Cytology service: standardising laboratory-based screening and reporting, while minimising turn-around times
- Client management at primary care level: establishing mechanisms for informing clients of results and for tracking clients who need recall for re-screening or referral for further management
- Colposcopy and treatment services: ensuring women's access to these services, by establishing mechanisms for referral to and feedback from services providing treatment for pre-cancerous lesions
- Monitoring and evaluation: ensuring mechanisms are in place to collect and analyse key cervical screening data for monitoring and evaluating the screening programme

Cytology-based screening programmes have proven difficult to implement and sustain in low-resource settings, because of the above-listed inherent requirements of a cytology-based programme. These include highly trained personnel, well-equipped laboratories, transport of specimens, and an effective system for collecting information and following up patients. High quality laboratories and colposcopy services for diagnosis and treatment are often not consistently available and accessible in these settings.[37] In addition, the demands of other competing health needs often result in a lack of resources or political will to make cervical cancer screening a priority.

Although cytological screening is being carried out in some developing countries, there are no organised programmes and the testing is often of poor quality and performed inadequately and inefficiently among the population. As a result, there has been a very limited impact on the incidence of cervical cancer.[7] Cervical screening has been offered in Chile, Colombia, Costa Rica, Cuba and Mexico since the 1970s but this has not resulted in declines in disease and deaths, despite some settings attaining high coverage rates above 80%. Coverage has been variable across regions, with rural areas being particularly underserved. In addition, there have been no systematic efforts at call, recall and follow-up of screened women.[7] Other countries with opportunistic screening efforts like Brazil and Peru continue to demonstrate high rates of cervical cancer incidence and mortality, and even in Singapore where high levels of opportunistic screening are conducted, impact has been minimal.[7]

In sub-Saharan Africa, where the burden of disease is perhaps greatest, no organised or opportunistic screening programmes exist apart from South Africa.[7] It is essential

to provide cervical cancer screening services in sub-Saharan Africa as this region carries a high burden of disease.[11] Most of the least functional health-care delivery systems are in Africa. The challenge for Africa is to develop screening services integrated into existing health services in such a way as to improve the overall functioning of health-care systems.[4] Many countries are currently investigating the feasibility of visual methods as an alternative to cytological screening.

In light of the difficulties in implementing a cervical cytological screening programme in low-resource settings, more attention is now being paid to other methods of screening, especially those requiring single visits. Proponents of cytological screening methods still advocate that any failures are not attributable to inadequacies of the Pap smear test, but relate more to lack of political will and poor programmatic management, to which all screening methods are vulnerable.[48,49] The cytology test has been shown to be effective when well applied. Where cytology screening has failed to work, blame can be laid on the design or delivery of the screening service.[4] Choosing a suitable screening test is only one aspect of a screening programme. A more fundamental and challenging issue is how the programme is organised and implemented.

Screening programmes often focus on cytology services, but women who are found to have abnormalities on screening need follow-up, diagnosis and possibly treatment, in order to prevent the development of cancer or to treat cancer at an early stage. Efforts to increase coverage will be wasted if those who test positive are not followed up correctly. This requires effective links between programme components (e.g. from screening to diagnosis and treatment). Organised programmes with systematic call,

recall, follow-up and surveillance systems have shown the greatest effect (e.g. in Finland and Iceland), and also used fewer resources than unorganised programmes (e.g. in the USA).[7]

1.4.5. Cervical screening programme implementation in South Africa

South Africa launched a national cytology-based cervical cancer control programme in 2001, which involves provision of three free Pap smears for women over 30 years at ten year intervals.[6] It is projected that this will result in a 64% reduction in cumulative incidence of cervical cancer.[50] The ultimate goal of the policy is to screen at least 70% of women, nationally, in the target age group within ten years of initiating the programme.[6]

The national cervical screening guideline gives very little detail about implementation of the programme, but does inform the process of follow-up based on the Pap smear result.[6] The guideline also defines referral criteria to colposcopy services. It addresses the issue of recalling clients to inform them of their results within one to four weeks of having a Pap smear, with the responsibility to trace patients who have not returned for their results resting with the provider institution. Patients who miss colposcopy appointments should also be traced by the screening institution. In terms of quality control, the guideline requires the laboratory service to inform clinics of their adequacy rates, with retraining being instituted if this drops below 70%.[6]

In accordance with the principles of the district health system, the organisation of the programme is decentralised, with Pap smears provided at no cost at every primary health care facility as well as hospitals. Colposcopy services are supposed to be

provided at referral hospitals. The National Department of Health retains responsibility for policy, guidelines, education materials, coordination and budgeting. The district and local government health departments are tasked with delivering the programme.

Challenges in programme implementation in South Africa

Despite the policy framework that exists in South Africa, progress in cervical cancer screening has been slow and hard to achieve.[4] As in other settings, local studies have shown that barriers to an effective cervical screening programme exist both at community and health service level.[7] Lack of resources and available treatment services, low community awareness, poor quality of Pap smears, and inadequate rates of follow-up are foremost among the challenges documented.[8,9]

a. Health system capacity

The national cervical screening programme is not functioning effectively due to the underlying systemic problems with the South African health system.[9,10] It is due in part to the demands on the health system of competing health needs, such as HIV, tuberculosis and maternal mortality. Other constraints include lack of funding, infrastructure and human resources required to sustain screening programmes.[9] Task shifting has seen a change to nurse-led provision of Pap smears, but human resource challenges still exist.[10] The South African public health system is faced with an acute shortage of healthcare workers that function with extremely high workloads. In addition, inadequate attention has been paid to nurses' knowledge, skills and attitudes with regard to cervical screening.[10] Studies have shown that not enough nurses are trained to provide Pap smears[51], and nurses report reluctance to take on Pap smear

provision due to fear of increasing their workload.[13,51] In recent years, facilities and infrastructure have been greatly improved without visible improvements in the screening programme. For example, in the Free State, the numbers of cytology laboratories, colposcopy clinics and the distribution of primary health care facilities have improved, yet the proportion of women receiving Pap smears decreased by almost 50% reportedly due to increased workloads in primary health clinics post-1994.[14]

A functioning health system is necessary to coordinate the many aspects of a cytological screening programme.[10] Some argue that South Africa has not invested sufficiently in health system strengthening or in building the management capacity to implement an effective screening programme.[8]

b. Population awareness

Cervical screening coverage remains suboptimal in South Africa, due in part to poor public awareness which results in low participation in the screening programme. A nation-wide population-based study of over 20 000 women over 25 years revealed that 80% of women had never had a Pap smear.[17] A study from a rural area of South Africa indicated that 64% of 538 women attending primary health care clinics had ever heard of Pap smears and only 56% of these women had ever had a Pap smear.[52] Project Screen Soweto aimed to set up a cervical screening programme in Soweto in the early 1990s, but was terminated after five years due to poor performance. This was attributed largely to a lack of planned population awareness which resulted in poor participation.[53]

c. Screening coverage

Screening statistics at a national level are not readily available, and when they are available for specific provinces, they often show poor coverage. A review of the implementation of the cervical screening programme in South Africa suggested that even recent increases in screening have still fallen short of targets. The author also commented further that relatively large numbers of women in South Africa remain unscreened.[9] Worryingly, in some settings coverage appears to be declining. For example, in the Free State province in 2002, 4.1% of the studied population was screened, compared with 7.1% in 1985.[14]

d. Target age group

Screening continues to be performed in young women who are not in the defined target age groups for the South African screening programme. A multicentre study showed 16-30% smears were done on women less than 30 years;[8] a study in the Western Cape reported that 84% of Pap smears were done in women less than 30 years;[13] and another study set in the Free State province found 65% of smears to be performed in women under 35 years.[54] This is partly because screening has been done opportunistically (on younger women) as part of family planning or postnatal visits. Much of this is related to staff knowledge, attitudes and practices regarding cervical screening.[13]

e. Screening in HIV positive women

The National Guidelines on Cervical Screening makes no specific recommendations on screening age and frequency for HIV positive women.[6] Although no published data is available on cervical screening in HIV positive women outside of research

settings, there are anecdotal reports that the high proportion of smears done on women under 30 years in recent years probably reflects the smears done on HIV positive women.[55] Cervical smears are performed in this group for pre-screening before commencing ART and thereafter annually, in line with a current HIV/AIDS management protocols for HIV-positive women who are immune compromised (CD4 < 350).[9] Performing smears on HIV positive women who fall outside the screening programme target population may divert attention and resources from, and therefore undermine the screening programme.

f. Pap adequacy

Data regarding the adequacy of Pap smears are unavailable but are necessary for quality assurance.[10] In one study in the Western Cape, only 56% of the smears taken were considered adequate for evaluation by the laboratory, with nearly half of reviewed samples lacking a sufficient component of endocervical cells.[13] Poor Pap smear adequacy is especially a problem as it results in a significant waste of resources and missed opportunities for effective screening.

g. Referral and treatment

In many programmes in middle-income countries[50] and even developed countries[56], women with an abnormality on Pap smear commonly fail to return to the clinic for management. South African studies suggest that up to 50% of women with HSIL Pap smear results do not access a colposcopy clinic for diagnosis and treatment.[51,57,58] The loss to follow-up is blamed on multiple health facility visits that are required in a cytological screening programme, the limited capacity to track women who do not return for Pap results or colposcopy appointments, and poor referral systems.[11,51] An

economic evaluation of different screening methods in South Africa identified failure to attend for investigation and treatment of abnormalities as a major factor in reducing the cost–effectiveness of cytology.[38] Without adequate referral and treatment of women with precancerous lesions, any increases in screening coverage rates will fail to decrease cervical cancer incidence and mortality.

h. Health Information Systems

Establishing well-functioning information systems are essential for successful monitoring and evaluation of a cervical screening programme.[7,59] The District Health Information System (DHIS) in South Africa reports on only two cervical screening indicators, viz. screening coverage and smear abnormality rate.[60] The DHIS does not report on other process indicators, including screening of women outside target age groups, smear adequacy, smear abnormality, colposcopy referral and attendance, and HSIL treatment rates, which are pivotal in order to inform how well the programme is doing. For example, it is not known what percentage of all women with abnormalities screened in the last year in Johannesburg or Gauteng has been treated to prevent cervical cancer.

In conclusion, cervical cancer is a well recognised health problem in South Africa owing in some part to gaps in the implementation of the national cervical screening programme. Hence this research project was done to evaluate the programme in the district in order to identify key areas for improvement.

1.5 Purpose of the Study

1.5.1 Aims of the Study

The overall aim of the project is to evaluate the cervical screening programme in the Johannesburg Metro District, Gauteng Province, looking specifically at screening coverage, and referral for treatment of precancerous lesions.

1.5.2 Objectives of the Study

1. To determine and analyse process indicators used for monitoring the cervical screening programme in Gauteng, including:

   a. Cervical screening coverage
   b. The proportion of smears done for the target age group
   c. Smear abnormality rate
   d. Smear adequacy rate

2. To assess the availability and use of referral services for diagnosis and management of pre-cancerous lesions, including:

   a. To describe the services that exist for referral of women with abnormal smears
   b. To determine waiting times for appointments and treatment at referral centres
   c. To determine the proportion of women with abnormal smears who receive and attend appointments at referral centres
   d. To determine where women are lost to follow-up in the screening programme

3. To identify factors associated with attendance of colposcopy appointment, and waiting time between Pap smear and colposcopy.

CHAPTER TWO

2. MATERIALS AND METHODS

In this Chapter, the methods used to conduct this study are described. Details are provided on the study setting, design, and the sampling strategy employed. Furthermore, the collection of the data is described and the methods of data analysis and statistical testing are specified.

2.1 Study Setting

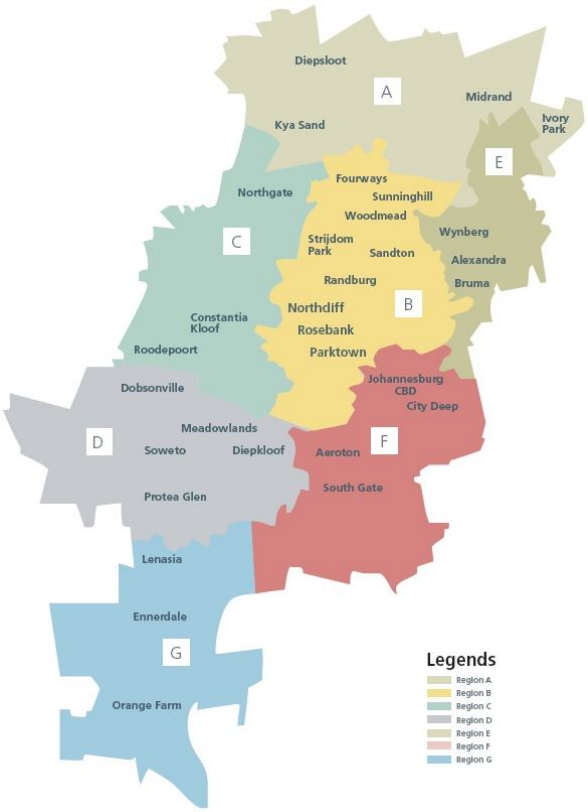

Figure 2.1 Map of the Johannesburg Metro District

Source: City of Johannesburg, 2008 [61]

The study was conducted in the Johannesburg Metro Health District in the Gauteng Province of South Africa, between March 2008 and March 2009. Johannesburg Metro District, a large urban metropolitan district, has a population of approximately 3.2 million people, with females accounting for 50% (over 1.6 million) of its general population.[62] It is the most densely populated district in the country, and ranks amongst the highest in terms of per capita district health expenditure.[63]

In line with the national cervical screening policy, Pap smears are provided in the district, to women aged 30 years and older accessing primary health care services, at no cost.[6] A client would have a cervical Pap smear done by facility staff at a primary health care (PHC) clinic, and then be asked to return for the result after an interval of around three weeks. If an abnormality is detected on the smear that requires further investigation and management, she is then instructed to make an appointment at an appropriate referral hospital to access colposcopy services.

There is a dedicated data recording tool for collecting cervical screening programme data at the clinic level. The Pap register records client details, Pap smear results and referral information where relevant. In addition, information about referrals is recorded in a referral book, which contains folio copies of all referral letters issued. Monthly collation sheets (used to tally cervical screening information) are also kept at the facilities and reported to the DHIS. At the hospitals, all colposcopy appointments made are captured in a register, as is a record of those that were attended. This register contains client names but no contact details or referring clinic. Some hospitals also keep a record of colposcopies performed.

2.2 Study Design

This was a largely descriptive study, involving quantitative methods. It involved secondary analysis of cervical screening data recorded in the DHIS and the National Health Laboratory Service (NHLS) databases; and retrospective reviews of monthly Pap registers and colposcopy appointment and treatment registers at a sample of PHC clinics and their referral colposcopy services in the district. Analytical statistics were employed to determine factors associated with colposcopy attendance.

2.3 Sampling

For the first objective, all cervical screening data reported to the DHIS for the study period were included in the analysis. No sampling was done.

For the second and third objective evaluating the referral process, the study sites were public sector PHC clinics providing cervical screening services in the district. The study extended to the referral hospitals that patients were directed to for treatment of abnormal smears.

The Johannesburg Metro District comprises of seven sub-districts named A to G, which collectively have 116 fixed public sector clinics, either run by local government (84 clinics), provincial government (30 clinics) or non-governmental organisations (NGOs) (2 clinics).

Stratified sampling was employed to select PHC clinics included in this study. The strata were sub-districts A to G, and the three different health authorities (local

government, provincial government and NGO). This ensured that clinics from each sub-district, and clinics managed by each authority were represented in the study.

To operationalise the sampling strategy, selection of clinics within the strata was done randomly where possible. In each sub-district, one local government and one provincial clinic were selected except for two sub-districts (A and B) that do not have provincial clinics. The two NGO-run clinics in the district (in sub-districts A and C) were sampled purposively. Thus, a total of fourteen clinics were included in the study (Table 2.1).

Table 2.1 Sampling strategy for selecting PHC clinics and referral hospitals

Sub-district	Fixed Health Facilities by Authority Total number (Sample)				Hospitals
	LG	Province	NGO	Total	
A	10 (1)	0 (0)	1 (1)	11 (2)	
B	7 (1)	0 (0)	0 (0)	7 (1)	RMH
C	11 (1)	1 (1)	0 (0)	12 (2)	
D	20 (1)	13 (1)	0 (0)	33 (2)	CHBH
E	9 (1)	1 (1)	1 (1)	11 (3)	
F	14 (1)	3 (1)	0 (0)	17 (2)	CMJAH
G	13 (1)	12 (1)	0 (0)	25 (2)	
Total	84 (7)	30 (5)	2 (2)	116 (14)	

Source: City of Johannesburg, Health Facilities, 2008 [64]

The sampling strategy also allowed for clinics and their respective referral hospitals to be included in the study. Thus, each of the three hospitals with colposcopy clinics in the district (Raheema Moosa, Charlotte Maxeke Johannesburg Academic and Chris Hani Baragwanath hospitals) including one hospital in the neighbouring Ekurhuleni District (Edenvale Hospital) which received referrals from study sites, were included.

It was necessary to include Edenvale Hospital, even though it does not fall within the study area, because patients from some clinics located in JMD, were actually referred to this hospital in Ekurhuleni, as it was geographically more accessible.

In clinics and hospitals that were selected, all records kept on cervical screening (Pap registers, referral letters, monthly collation sheets, colposcopy appointment and treatment registers) for the study period were included.

2.4 Data Collection

To evaluate different components of the cervical screening programme, various data sources were used, including:

- the DHIS database for cervical screening data from Gauteng and JMD
- the NHLS database for information on Pap smear adequacy
- DHIS midpoint estimates for target population sizes
- Pap registers at PHC clinics
- Colposcopy appointment and treatment registers at referral hospitals

Objective 1: Data were extracted from the DHIS as follows. There are over three millions elements related to each process, health outcome and impact indicator stored in this database, so a request was made to the Gauteng Department of Health, to supply all data relating only to cervical screening for the period April 2000 to March 2008, for the Gauteng province. This was supplied in the form of Microsoft Excel spreadsheets and pivot tables. The following data were then extracted from these spreadsheets for the Johannesburg Metro District for the 2007/8 financial year (April 2007 to March 2008):

- New screening Pap smears performed per health facility
- New smears performed for women in each age category, i.e. <20, 20-29, 30-39, 40-49, 50-59, >60 years
- Abnormal smears detected in each Pap smear abnormality category, i.e. ASCUS, LSIL, AGUS, HSIL, invasive cancer

Data on smear adequacy was requested from the NHLS Cytology department. This was provided as Microsoft Excel spreadsheets and included data for the 2007/8 financial year only for the fourteen clinics sampled to evaluate the referral process. Due to technical difficulties in extracting information on smear adequacy, it was not possible for the NHLS to provide data on all clinics in the district. For each clinic, the information extracted from the NHLS database included:

- Number of adequate smears (with endocervical component)
- Total number of smears screened by the NHLS laboratories

The denominator used for determining the coverage rate was the "population at risk" which is defined as the number of women in the target age group above 30 years. The DHIS uses population projections from Statistics South Africa (Stats SA) derived from census data, to calculate population denominators for Gauteng and for Johannesburg Metro District:

- Estimated number of insured and uninsured women over thirty years, at the midpoint of each year for which coverage was calculated

The numerator reflects only screening Pap smears done in the public sector, whereas the denominator includes insured women (using the private sector) in the target age group. Despite this, this formula was employed in this study as it is used by the DHIS

to calculate coverage, and this study sought to reflect on the current status of the programme in the district.

Objective 2: To describe practices at screening clinics and referral facilities, informal interviews were conducted with key staff at each facility, exploring current practices with regards to screening and referral.

Objective 2 and 3: involved a review of Pap registers at the selected clinics to identify and collect data on women who had Pap smears that were found to have "high grade" lesions (HGL) thus requiring referral to colposcopy. This was followed by a review of the colposcopy clinic appointment lists and treatment records to ascertain whether these women had made and attended appointments at colposcopy clinics. For the purposes of this study, high grade was defined as any Pap smear that reported high grade squamous intraepithelial lesions (HSIL), atypical glandular cells of unknown significance (AGUS) or invasive cancers; because routine management protocols state that these abnormalities require referral for diagnostic colposcopic procedures.

Data were extracted from clinic Pap registers on women found to have high grade lesions on Pap smear during the period April 2007 to March 2008. The following data were captured onto a data collection sheet (Appendix A) adapted from existing tools:[51]

- Date of Pap smear
- Name
- Date of birth; age
- Contact details (address and telephone number)

- HIV status (if available)
- Pap smear result
- Date informed of result and referred
- Referral facility

At the colposcopy clinic, records for the period April 2007 to March 2009 were reviewed to ascertain whether the referred women made and attended colposcopy appointments. The following data were extracted from the colposcopy clinic records, and also entered onto the data sheet in Appendix A:

- Date of appointment
- Attendance of appointment

The period that the colposcopy records were reviewed extended to March 2009, to allow for a lag time between having a Pap smear and attending a colposcopy appointment. One particular hospital was found to be booking appointments up to twelve months later due to large patient volumes. In line with other studies investigating Pap smear follow-up, non-adherent patients are operationally defined as patients with abnormal findings on Pap smears who do not have documented evaluations or treatments within a specified amount of time, which in this study was determined as twelve months.

Every effort was made to confirm that the data collected was complete. In Gauteng Province, it was not possible to assess concordance between the Pap registers and patient folders as the latter are not retained at the facility. For consistency, multiple sources of data were reviewed, where available, at each facility. At the clinics, the

folio copies of referral letters in the referral books confirmed what was recorded in the Pap registers. At the hospitals, both appointment books and treatment records (electronic and hard copies where available) were reviewed to capture information on colposcopy attendance.

2.5 Data Management and Analysis

Data from record reviews were coded and captured onto Microsoft Excel spreadsheets. To protect the integrity of the database, the Excel data was immediately write-protected and stored in two safe places (CD-ROM and dedicated memory stick) and then only copies were worked with. Summary data was examined to detect any data errors and once the dataset was found to be "clean", was then imported to the STATA (Release 10, StataCorp, 2007) programme, used to conduct the analysis.

Objective 1: The indicators used to evaluate the screening programme were calculated as indicated in Table 2.2.

These indicators, calculated utilising tools previously developed for programme managers,[51] were compared to programme targets. The indicators were calculated for the district, but in addition the coverage rates were disaggregated for each sub-district. Cervical screening coverage and smear abnormality rates were also presented according to age category. In addition, cumulative cervical screening coverage data since the inception of the screening programme in November 2000 was presented for trend analysis.

Table 2.2 Process indicators for evaluating cervical screening programmes

Screening services	
Coverage	No. of new smears in women > 30 years x 100 Total target population
Smear adequacy	No. of smears with endocervical component x 100 Total no of smears done
Smear abnormality	No. of abnormal smears x 100 Total no of smears done
Client management at primary care level	
Clients with abnormal smears informed of their results	No. of women with HGL informed of results x 100 Total no. of women with HGL
Colposcopy and treatment services	
Colposcopy appointment	No. of women with HGL with colposcopy appointment x 100 Total no. of women with HGL
Colposcopy attendance	No. of women who attend colposcopy appointment x 100 Total no. of women with HGL
Colposcopy adherence	No. of women who attend colposcopy appointment x 100 No. of women with HGL informed of results

Source: CHIP, 2004 [51]

Objective 2: For the evaluation of the referral process, descriptive analysis was performed to summarise the characteristics of women from the clinics found to have abnormal Pap smears requiring referral. Proportions and measures of central tendency and spread were reported as appropriate for clients' age, HIV status, and the clinic, sub-district or health authority they originated from.

Measures of association determined any differences between sub-districts and health authorities. The chi squared test was used to test for differences in proportions;

parametric unpaired Student t-test for comparison between means; non-parametric Kruskal-Wallis between medians; and one-way ANOVA with post-test (Tukey) for more than three groups of data. Differences in values were considered statistically significant if the 'p' value was less than 0.05.

In analysing loss to follow-up, methodology employed in a similar study was replicated.[65] Process effectiveness was measured by the number of appointments set up and performance was measured by compliance with referral appointments. Based on published findings on underserved women, three effectiveness cut-off points were selected: 80% contact and notification rate, and 72% referral appointment rate for system effectiveness, and a 60% appointment compliance rate for system performance. These measures were chosen as cut-offs as they were average rates found in control groups in studies evaluating interventions aimed at improving colposcopy appointment adherence.[65]

The waiting time for attendance of colposcopy appointment was calculated as the difference between date of Pap smear and attendance of colposcopy appointment. This interval was selected as it reflected the clients' complete interaction with the health system, and represented the many stages in the screening and referral process where women may have been lost to follow-up.

Objective 3: Multivariate logistic regression models were fitted to determine patient and health service factors associated with attendance of colposcopy appointments and linear regression models were used to determine factors associated with time to colposcopy. Possible predictors included age; HIV status; the clinic, health authority

and sub-district women were referred from; and the hospital to which they were referred. Model building proceeded backwards from a first "full" model including all the above variables, from which the non-statistically significant variables were withdrawn sequentially. The assumptions of the linear regression model were checked by examining the residuals for normality and constancy of spread.

The outcome variables were:

- Colposcopy attendance (binary)
- Time to colposcopy (continuous)

The predictor variables included:

- Age (ordinal)
- Contact details recorded in Pap register (binary)
- Clinic (nominal)
- Health authority (nominal)
- Sub-district (nominal)
- Referral hospital (nominal)

2.6 Ethical and Legal Considerations

Research approval was granted by the Committee for Research on Human Subjects (Medical) of the University of the Witwatersrand. Clearance was given for research involving patient records (Ethics clearance number: M080439; Appendix B).

This research project was commissioned by the Johannesburg Metro District, Gauteng Department of Health. Access to data in the DHIS was granted by the Health

Information Systems Directorate, Gauteng Department of Health. Managers at the Johannesburg Metro District and City of Johannesburg municipality granted permission to access the PHC facilities and referral hospitals. Thereafter, permission was requested and granted from each sub-district manager, and also from the facility managers, prior to visiting the facilities for data collection.

Facility confidentiality was maintained by identification only with a code. An assurance was also made that any pertinent findings would be reported by the primary investigator to the managers and staff so that the facility may benefit from recommendations arising out of this research study.

For the most part, secondary data did not include patient names. However, to track patients through the referral process, it was necessary to record patient identifiers. These were known only to the researcher and all records and documentation were housed securely at the School of Public Health, University of Witwatersrand. Electronic records were maintained in password-protected computers.

CHAPTER THREE

3. RESULTS

In this Chapter, the study findings are presented. Firstly, results of secondary analysis of the cervical screening data from *all* facilities in the JMD, derived from the DHIS are presented. Secondly, primary data collected for this study is presented, on the referral of women with high grade lesions and invasive cancer from *sampled* PHC clinics to colposcopy units for diagnosis and treatment. Thirdly, the factors associated with colposcopy attendance and waiting times are presented.

3.1 Cervical Screening Indicators

3.1.1 Cervical screening coverage

Data presented here represents cervical screening data from all 116 primary health care clinics and the three hospitals in the district. In each sub-district, the majority of clinics belong under the authority of the local government. The distribution of clinics by health authority type is depicted in Table 3.1.

Table 3.1 Distribution of PHC clinics by health authority, JMD

Sub-district	LG	Province	NGO	Total	Proportion LG
A	10	0	1	**11**	91%
B	7	0	0	**7**	100%
C	11	1	0	**12**	92%
D	20	13	0	**33**	61%
E	9	1	1	**11**	82%
F	14	3	0	**17**	82%
G	13	12	0	**25**	52%
Total	**84**	**30**	**2**	**116**	72%

Source: City of Johannesburg, Health Facilities, 2008 [64]

a. Cumulative coverage

The cumulative coverage data includes only screening data on women as defined by the national programme, i.e. women who are 30 years old and above. Figure 3.1 describes the trend in the cumulative cervical screening coverage for the Johannesburg Metro District and Gauteng Province since the programme inception in 2000 until the end of the 2007/8 financial year (March 2008). The coverage required to attain the national target of 70% cumulative coverage by 2010, indicated by the straight line, is shown for comparison. Cumulative coverage for JMD (30.7%) is higher than the provincial average (21.4%). Cumulative cervical screening coverage in both the district and the province are below national targets.

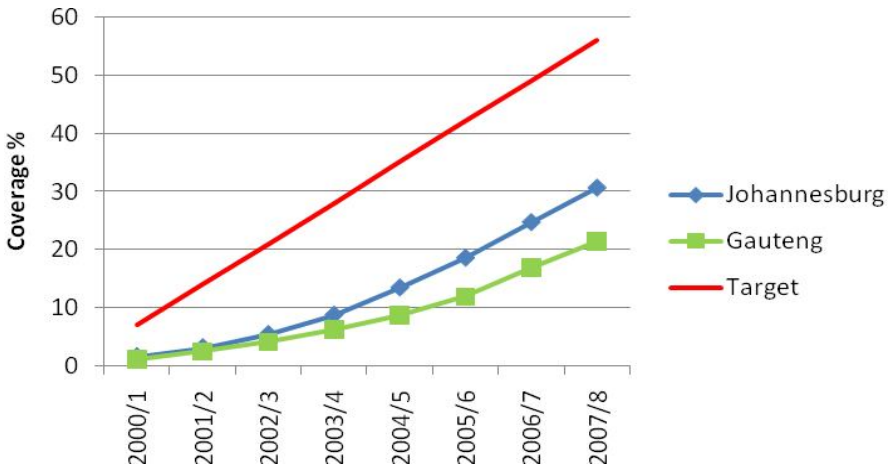

Figure 3.1 Cumulative cervical screening coverage: JMD, Gauteng 2000 – 2008

The cumulative cervical screening coverage by March 2008, shows significant variation across the districts of the Gauteng Province and the sub-districts in JMD. Two of the metropolitan districts, JMD and Ekurhuleni, have the highest coverage in the province (Figure 3.2), and sub-districts A and C have the highest cumulative coverage in the JMD (Figure 3.3).

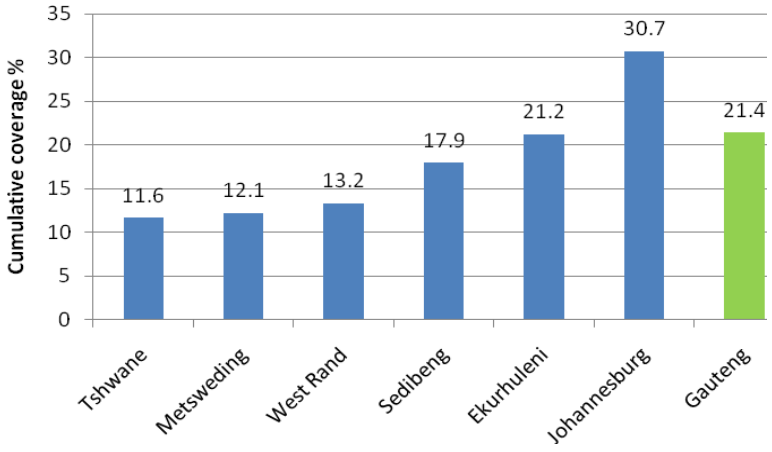

Figure 3.2 Cumulative screening coverage: districts in Gauteng province, 2008

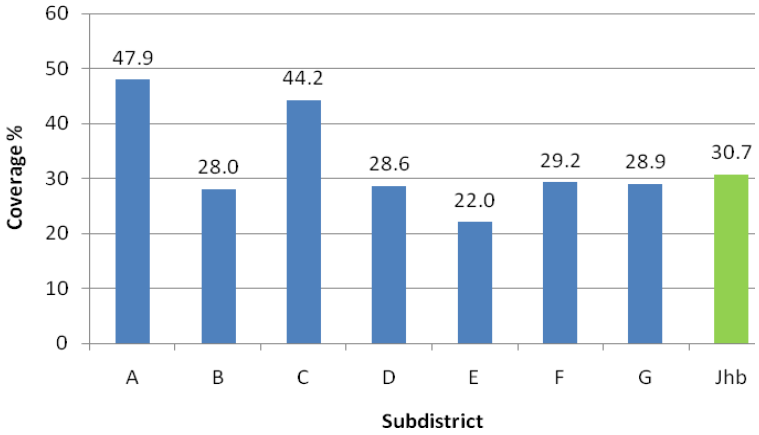

Figure 3.3 Cumulative screening coverage: sub-districts in JMD, 2008

b. Pap smears per clinic

Table 3.2 shows that of all Pap smears reportedly performed for women over 30 years in 116 PHC clinics and 3 hospitals in 2007/8, a median of 267 smears were performed per health facility in the district in that year, with NGO clinics performing most smears per facility, followed by local government then provincially-run health

facilities. The differences between health authority was statistically significant ($p<0.001$).

Table 3.2 Distribution of all smears done in JMD, 2007/8

Health Authority (n)	Median	Range
Local govt (84)	296	6 – 749
Provincial govt (33)	153	0 – 874
NGO (2)	581	471 – 690
All (119)	267	0 – 874

3.1.2 Appropriate age for screening

Figure 3.4 demonstrates the number of Pap smears done in JMD, by age group. Data for three financial years (2005/6 to 2007/8) are presented to demonstrate a trend over time. The highest number of Pap smears were done in women aged 30-39 and those aged 40-49, with lower numbers of smears done in older age groups. The data also shows that smears are being done in younger women who are outside the target age group for the cervical screening programme.

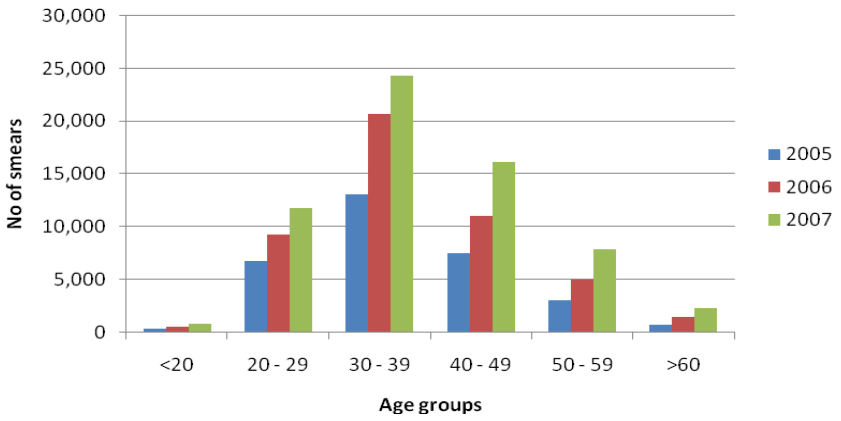

Figure 3.4 Number of Pap smears done by age group: JMD, 2005-7

As shown in Figure 3.5, Pap smears in women less than 30 years of age consistently accounted for about 21% of all smears done in each of the three years.

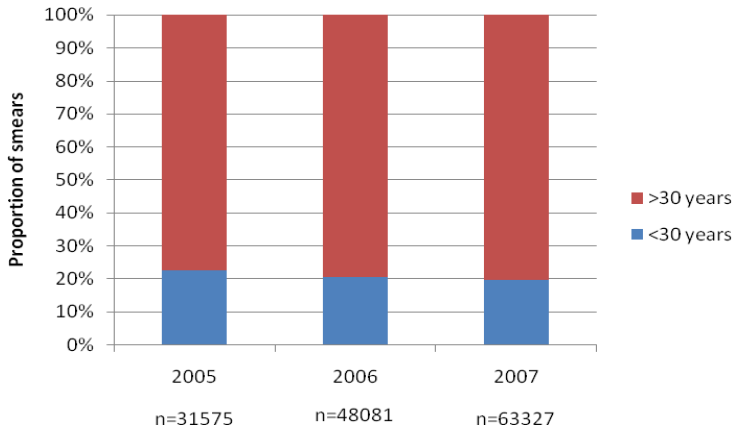

Figure 3.5 Proportion of smears done in target age group: JMD, 2005-7

3.1.3 Cervical screening loss to follow up

The health facilities report information on the numbers of patients who do not return for their Pap smear results to the DHIS, and these are defined as women lost to follow-up. Large proportions of women across every age group do not return to the clinics for their results. In Figure 3.6, there is a trend of increasing loss to follow up from 2005 to 2007 for each age group (chi squared test for trend p=0.046). An average of 30% loss to follow up is seen in 2005 and 2006, but this increased to almost 36% in 2007.

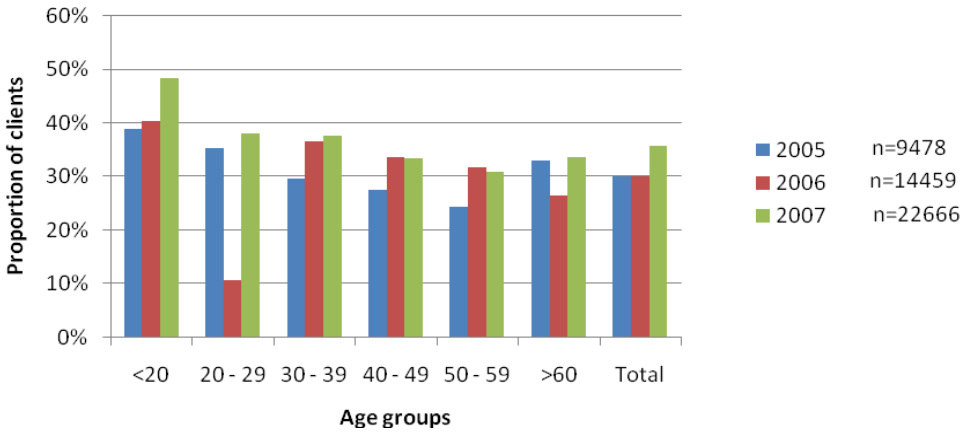

Figure 3.6 Proportion of clients lost to follow-up: JMD, 2005-7

3.1.4 Cervical smear abnormality

In 2008, of 63 327 Pap smears done in the Johannesburg Metro District, 10.7% were found to be abnormal. Figure 3.7 shows that of the total Pap smears done each year, low grade lesions (including LSIL and ASCUS) are more commonly seen than high grade lesions (including HSIL and invasive cancer) and AGUS.

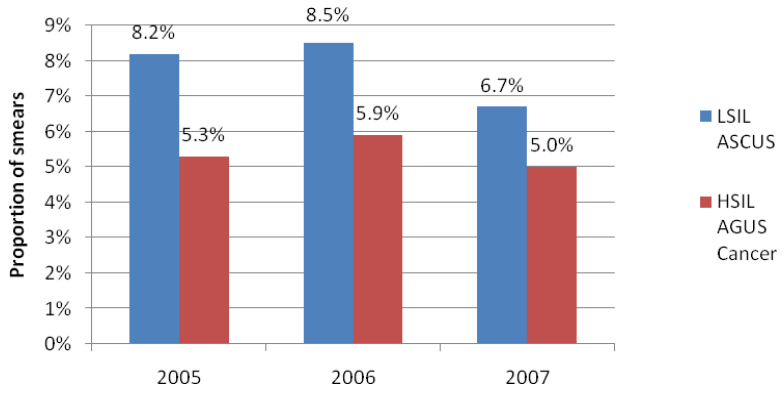

Figure 3.7 Proportion of smears with low and high grade lesions: JMD, 2005-7

Of the total high grade lesions detected, 17% (550 of 3 154) were in women less than 30 years. Figure 3.8 describes the distribution of abnormal smears amongst different

age groups for 2007/8. With increasing age, a smaller proportion of smears show low grade lesions. 4.4% (2 395 of 63 327) of women less than 30 years had high grade lesions or invasive cancer.

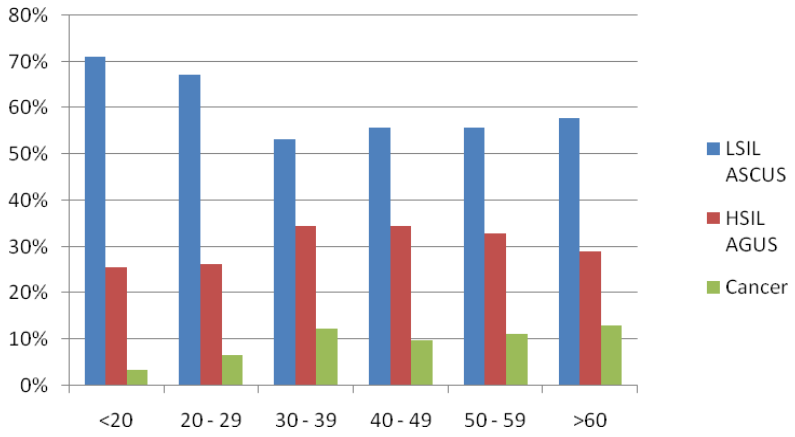

Figure 3.8 Proportion of Pap smear abnormalities by age group: JMD, 2007/8

To demonstrate more clearly the abnormalities by age group, data from 2007/8 only are presented in the figures below. During this period, 7 403 smears were abnormal, of which 1 699 (23.0%) were in women aged less than 30 years and 5 704 (77.0%) in women older than 30 years. Up to 71% of all abnormal smears in the under 30 years age group are low grade, whereas 56 – 58% were low grade at older ages. Conversely, a higher proportion of abnormal Pap smears in older ages show high grade lesions and cancers compared to younger women (Figure 3.9).

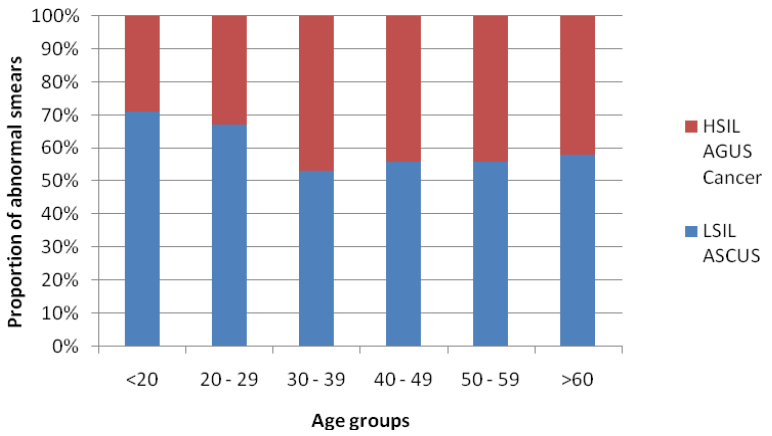

Figure 3.9 Proportion of low and high grade lesions by age group: JMD, 2007/8

3.2 Referral to Colposcopy Services

3.2.1 Cervical smear adequacy

During April 2007 and March 2008, 4 723 Pap smears were done in the 14 clinics sampled for the study. The adequacy rates of these smears are presented in Figure 3.10 and compared to the target of 70% contained in the national guidelines.

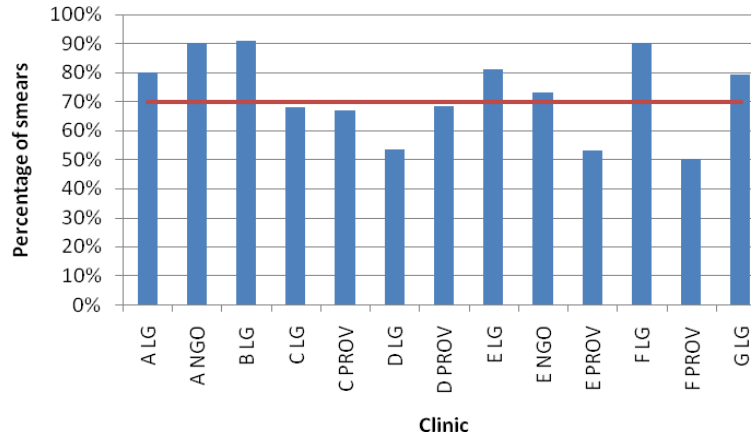

Figure 3.10 Smear adequacy rates in sampled clinics, JMD, 2007/8

3.2.2 Clinic screening practices

During data collection for this study, varying practices with regard to screening were observed at the sample clinics. One particular clinic manager held two large "cervical screening days" during the year. Community based health care workers raised community awareness of the screening drives, and clinic staff were mobilised to provide the service after-hours on a Saturday. Ultimately, hundreds of Pap smears were performed on those two days in the year. In some clinics, managers used screening targets each month, and this ensured a concerted effort was made to perform a certain number of Pap smears monthly. The latter practice may relate to practices of the authority running the clinic- local government clinics have "scorecards" to monitor performance over many service areas and these translate into target setting for the clinics. Many facilities targeted women attending family planning clinics for cervical screening, resulting in large proportions of Pap smears being done in young women in the reproductive age groups.

3.2.3 Detection of high grade lesions

Review of the clinic Pap registers from 14 clinics showed 557 women with high grade lesions, out of 4 723 total Pap smears performed. Table 3.3 displays the number of women with high grade lesions by clinic and Table 3.4 by health authority. The NGOs identified the highest percentage of women with high grade lesions requiring referral (Table 3.4).

Table 3.3 Distribution of high grade lesions by clinic

Clinic	No of smears	No of high grade lesions	Proportion high grade %
A LG	415	29	7.0
A NGO	747	111	14.9
B LG	167	23	13.8
C LG	249	17	6.8
C PROV	347	47	13.5
D LG	379	54	14.2
D PROV	216	35	16.2
E LG	470	40	8.5
E NGO	538	96	17.8
E PROV	273	8	2.9
F LG	372	33	8.9
F PROV	73	3	4.1
G LG	238	30	12.6
G PROV	239	31	13.0
TOTAL	**4 723**	**557**	**11.8**

Table 3.4 Distribution of high grade lesions by health authority

Health Authority	No of smears	No of high grade lesions	% HSIL
LG	2290	226	9.9
NGO	1285	207	16.1
Provincial	1148	124	10.8
TOTAL	4723	557	11.8

Figure 3.11 shows the number of high grade lesions detected by a clinic correlates with the number of Pap smears performed (Spearman's rho= 0.70; p=0.005).

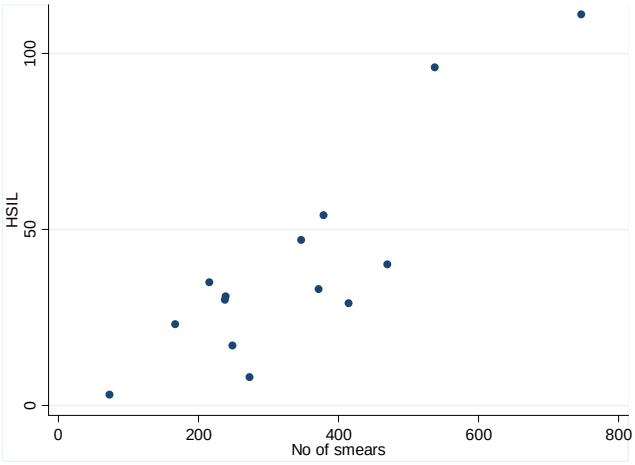

Figure 3.11 Correlation between Pap smears performed and HGLs detected

3.2.4 Descriptive analysis of women with high grade lesions

The following is a description of selected demographic and clinical characteristics of the 557 women who were found to have high grade lesions on Pap smear.

a. Age

The mean age of women with high grade lesions was 36.2 (SD 9.2) years, exhibiting a range of 17 to 77 years. 20.6% of these women were under 30 years of age (Figure 3.12). There were significant differences in the ages of women with high grade lesions at the various clinics sampled (p=0.004). Women screened by the provincial clinics have a higher mean age than the other clinics (p<0.001).

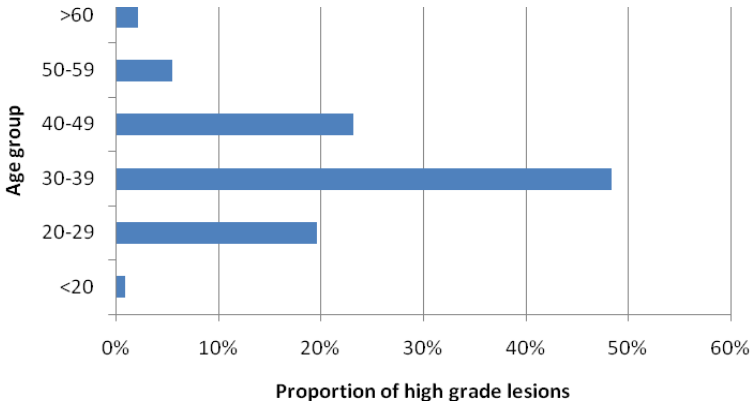

Figure 3.12 Distribution of high grade lesions by age group

b. HIV status

HIV status was not routinely recorded in the Pap registers or referral letters, and the data presented includes only those that were known and recorded to be HIV infected. An HIV positive diagnosis was noted in 118 out of 557 women (21%), while the HIV status of the rest of the women with high grade lesions were unknown.

The percentage of high grade lesions in HIV positive women by clinics is shown in Figure 3.13. Three clinics detected HSIL and cancer in large proportions of HIV positive women. A(NGO) did Pap smears primarily for pre-screening for ART. The majority of Pap smears done at G(Prov) were in the ART clinic. E(Prov) reported prioritising cervical screening in HIV positive women.

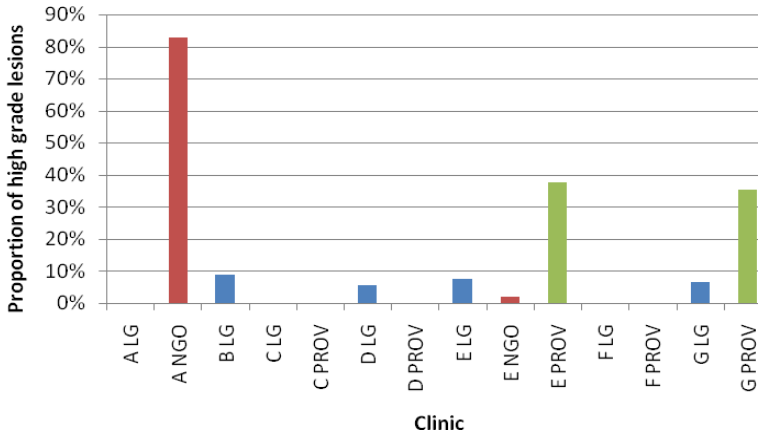

Figure 3.13 Proportion of high grade lesions in HIV positive women, by clinic

From the results presented above, a distinction can be made between clinics conducting screening of HIV positive women (for pre-ART initiation and routine annual follow-up), and those doing general screening of the target age group. Table 3.5 shows the difference in age between HIV-screening (HIV positive women) and general screening (unknown HIV status), in the 539 clients whose ages were recorded. Women identified with HSIL from HIV clinics were on average younger than those picked up from routine screening. This difference was statistically significant (p=0.045).

Table 3.5 Relationship between age and HIV status in women with HGLs

Screening setting (n)	Mean age	95% CI	p-value
HIV screening (112)	34.65	33.31 – 35.99	0.045
General screening (427)	36.60	35.69 – 37.52	

3.2.5 Data recording

a. Contact details

Figure 3.14 shows that contact telephone numbers were recorded in the clinic Pap registers for 269 of 557 (48%) women with high grade lesions.

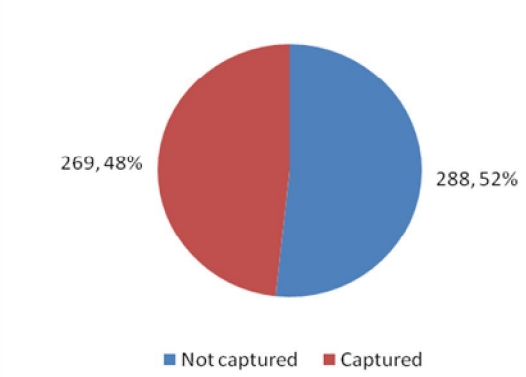

Figure 3.14 Proportion of clients in whom contact details were captured (N=557)

The percentage of women for whom contact details were recorded varied significantly between different clinics ranging from 0% to 100% (Figure 3.15); and by health authority (Figure 3.16). Provincial clinics were most likely to record contact numbers (82; 66.1%), followed by NGO (91; 44.0%) and local government (96; 42.5%) clinics. The differences were statistically significant ($p<0.001$).

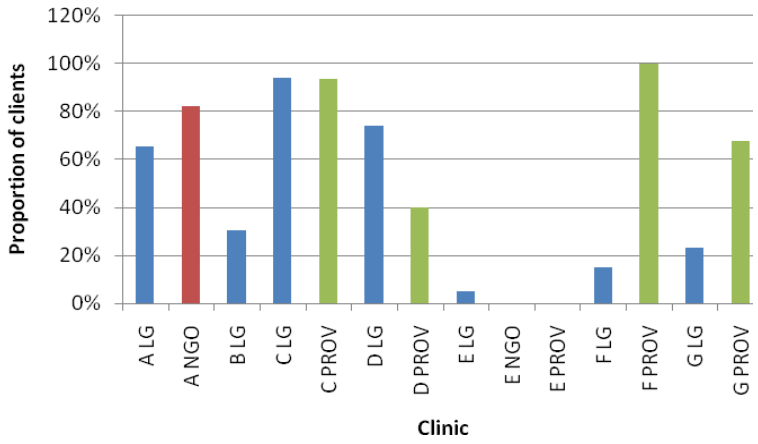

Figure 3.15 Proportion of contact details recorded, by clinic

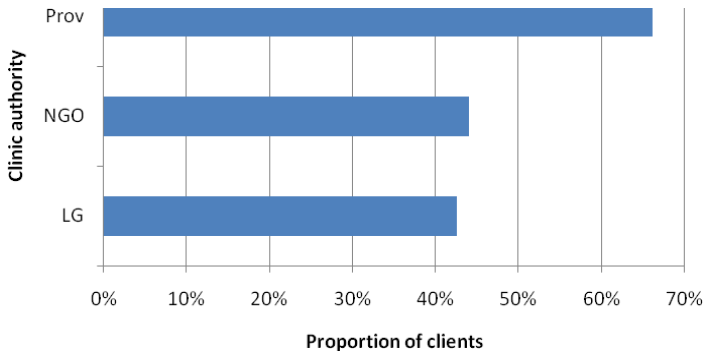

Figure 3.16 Proportion of contact details recorded, by health authority

b. Completeness of results entered in Pap register

Record keeping was further assessed by determining the number of Pap smears done and the number of results entered in the Pap register. This was compared for each clinic, and is displayed in Figure 3.17. On average, 84.7% of Pap smear results had been entered in the Pap register, and this ranged from 40.2% to 98.8% between clinics. There was no statistically significant differences in data completeness between health authorities (p=0.38) or sub-districts (p=0.44).

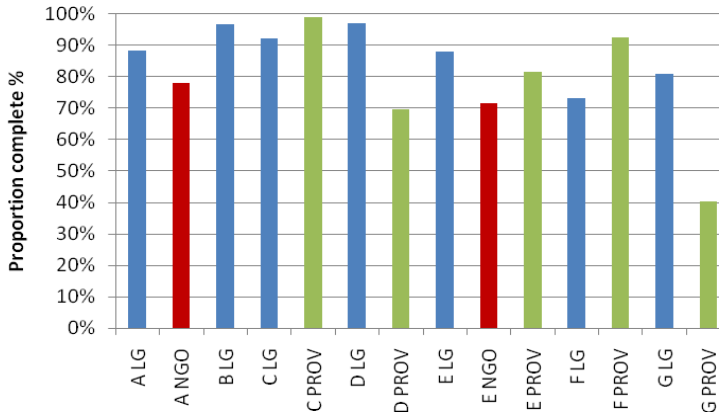

Figure 3.17 Proportion of results entered into Pap register, by clinic

3.2.6 Referral hospital

The 14 study sites refer women to four hospitals for colposcopy. These include Chris Hani Baragwanath Hospital (CHBH), Raheema Moosa Hospital (RMH), Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) and Edenvale Hospital (EH).

a. Practices and activities at referral hospitals

Each referral hospital had a very different capacity and pattern of colposcopy activity. CHBH has an extremely busy colposcopy clinic, operating each weekday, Monday to Friday, performing on average 100 to 120 colposcopies per week. The time to next available booking is nine months. Appointments are generally made directly by the referring facility staff via a telephone call to the colposcopy clinic. At RMH, twenty colposcopies are done per week on four days in the week. Clients have to present themselves at the colposcopy clinic to make an appointment, and may have to wait about two months for a booking. CMJAH sees about thirty to forty patients per week, each day of the week. Clients make their own appointments, and the current waiting time for booking an appointment is around four months. EH, during the time the study

was conducted, were operating a very inconsistent colposcopy service due to issues with the functioning of equipment. They did only six to seven colposcopies on average per month. Clients made their own appointments and were given bookings within two to three months.

All hospitals use colposcopy booking registers that record client names only. No contact details are captured for patients in any of the registers. Defaulters were neither traced by the colposcopy clinic, nor reported to the referring PHC clinics.

b. Referral of clients with high grade lesions

Of the 557 high grade lesions detected, 318 women were given their results and referred for colposcopy. Women with high grade lesions in this study were referred to the following hospitals for colposcopy: CHBH (111; 35%), RMH (134; 42%), CMJAH (67; 21%) and EH (6; 2%). Clinics referred patients to the various hospitals according to geographic location, and there was no difference in referral patterns on the basis of health authority. Consistently, each hospital received referrals from certain sub-districts – RMH (sub-districts A, B and C), CMJAH (sub-districts E and F), EH (sub-district E), and CHBH (sub-districts D and G).

3.2.7 Time to colposcopy

Of 318 women referred, 211 made appointments and 155 attended colposcopy clinic. The median time between Pap smear and attendance at colposcopy clinic was 4.4 months (IQR 3.1 – 7.1 months), ranging from 1.0 to 15.4 months. Clinics referring to the same hospital generally had similar waiting times to colposcopy appointment (Figure 3.18).

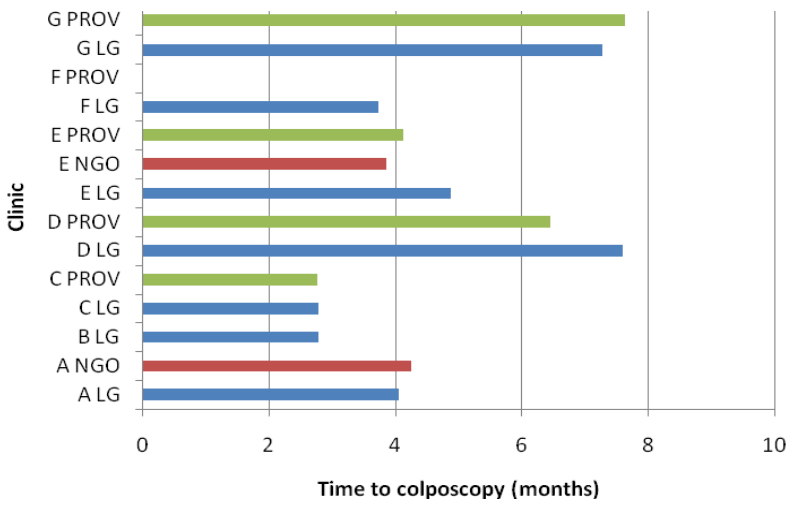

Figure 3.18 Median time to colposcopy, by clinic

Table 3.6 shows that there was no difference in median time to colposcopy between clinics under different authority (p=0.370), but there was variation by sub-district (p<0.001) and referral hospital (p<0.001).

Table 3.6 Median time to colposcopy attendance

	Time to colposcopy (months) median (IQR)	p-value
Health authority		
LG	4.6 (3.1 – 7.6)	0.370
NGO	4.3 (3.1 – 6.3)	
Provincial	4.1 (2.8 – 6.5)	
Sub-district		
A	4.3 (3.1 – 5.9)	<0.001
B	2.8 (2.0 – 4.5)	
C	2.8 (2.1 – 3.5)	
D	7.0 (4.7 – 8.4)	
E	4.5 (3.1 – 6.3)	
F	3.7 (3.5 – 4.0)	
G	7.5 (6.0 – 11.2)	
Referral Hospital		
CHBH	7.3 (4.9 – 8.8)	<0.001
RMH	3.5 (2.5 – 5.0)	
EH	3.2 (2.2 – 4.4)	
CMJAH	4.5 (3.5 – 6.7)	

3.2.8 Loss to follow-up

Of all 557 women identified to have pre-cancerous and cancerous lesions on Pap smear, 155 attended diagnostic and treatment facilities. Figure 3.19 describes where women were lost to follow-up in the cervical screening and treatment process. In measuring system effectiveness, the notification rate was 57% and referral appointment rate was 38%, and for system performance the appointment compliance rate was 28%.

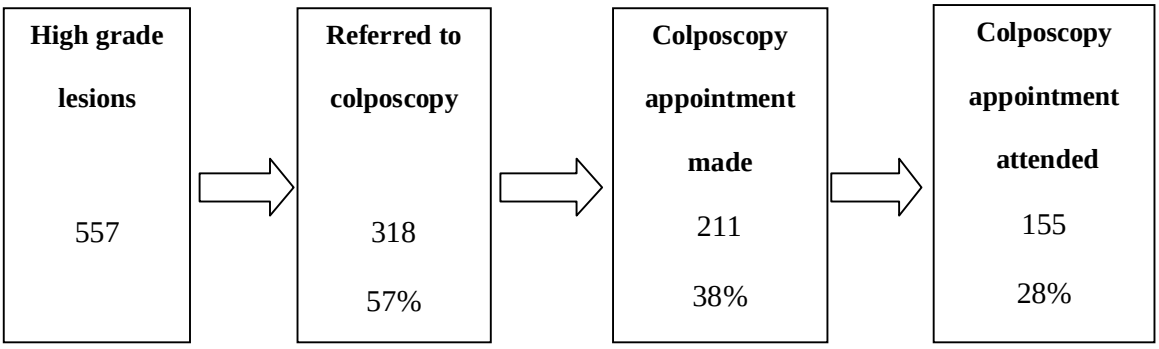

Figure 3.19 Loss to follow up of women with high grade lesions

There were significant differences between health authority and sub-district with regard to system effectiveness and performance (Table 3.7). While provincial clinics (83.9%) referred high proportions of women with high grade lesions, local government (48.2%) patients were most likely to make appointments, and provincial (32.3%) patients were most likely to attend colposcopy appointments. NGO-run clinics performed poorest in terms of referral of women to colposcopy services.

Sub-district B referred (87.0%) the highest proportion of women requiring colposcopy, and also had the highest proportion who attended their appointments (43.5%). Patients from sub-district E were least likely to be referred (34.7%), make appointments (19.4%) or attend appointments (15.3%).

Table 3.7 Differences in system effectiveness and performance

	HSIL n	Referred n (%)	Appointment n (%)	Attended n (%)
Health Authority		p<0.001	p<0.001	p=0.259
LG	226	153 (67.7)	109 (48.2)	65 (28.8)
NGO	207	61 (29.5)	51 (24.6)	50 (24.2)
Provincial	124	104 (83.9)	51 (41.1)	40 (32.3)
Sub-district		p<0.001	p<0.001	p<0.001
A	140	60 (42.9)	52 (37.1)	52 (37.1)
B	23	20 (87.0)	10 (43.5)	10 (43.5)
C	64	55 (85.9)	25 (39.1)	24 (37.5)
D	89	65 (73.0)	50 (56.2)	25 (28.1)
E	144	50 (34.7)	28 (19.4)	22 (15.3)
F	36	23 (63.9)	17 (47.2)	3 (13.9)
G	61	45 (73.8)	29 (47.5)	17 (27.9)

3.2.9 Colposcopy adherence

Colposcopy adherence reflects the proportion of women who were given their results and referred, and who then attended colposcopy appointments. Adherence ranged from 0% to 100%. Clinics differed significantly in adherence rates (Figure 3.20), with only A(NGO) achieving an adherence rate over 70%. Patients referred from NGO clinics had highest adherence of 82%, and patients from local government (42.5%) and provincial clinics (38.5%) had lower adherence rates (Figure 3.20).

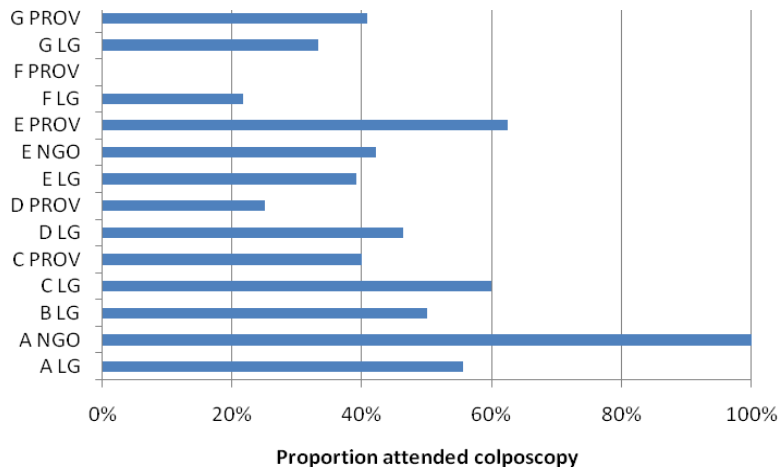

Figure 3.20 Colposcopy adherence rates, by clinic

3.3 Predictors of Colposcopy Attendance

On univariate analysis, sub-district, HIV seropositivity and recording of contact telephone number were associated with attending colposcopy appointment. Age and health authority were not statistically significant variables. Patients from sub-districts E and F were less likely to attend, compared to those from sub-district A; and women who were HIV positive and those whose contact telephone numbers were recorded were more likely to attend appointments (Table 3.8).

In the multivariate logistic regression model, health authority, sub-district and HIV seropositivity were significantly associated with colposcopy attendance. Patients from NGO clinics were less likely to attend appointments. Compared to sub-district A, patients from F were less likely to attend. HIV positive women were still more likely to attend appointments than those in whom HIV status was unknown. Recording contact details in the Pap register was associated with a higher chance of attending

colposcopy, but this was not found to be significant (p=0.090). Age did not influence attendance of colposcopy appointment (Table 3.8).

Table 3.8 Predictors of colposcopy attendance at referral hospitals

	Univariate Analysis		Multivariate Analysis	
	OR (95% CI)	**p value**	**OR (95% CI)**	**p value**
Health Authority				
LG	1	-	1	-
NGO	0.8 (0.5 – 1.2)	0.279	**0.4 (0.2 – 0.7)**	**0.005**
Provincial	1.2 (0.7 – 1.9)	0.495	1.0 (0.6 – 1.9)	0.892
Sub-district				
A	1	-	1	-
B	1.3 (0.5 – 3.2)	0.563	1.2 (0.4 – 3.6)	0.697
C	1.0 (0.6 – 1.9)	0.961	0.8 (0.3 – 1.9)	0.563
D	0.7 (0.4 – 1.2)	0.159	0.6 (0.2 – 1.3)	0.159
E	**0.3 (0.2 – 0.5)**	**0.000**	0.6 (0.3 – 1.3)	0.174
F	**0.3 (0.1 – 0.7)**	**0.011**	**0.3 (0.1 – 0.9)**	**0.035**
G	0.7 (0.3 – 1.3)	0.205	0.5 (0.2 – 1.2)	0.117
Age				
<30	1	-		
30-39	1.4 (0.9 – 2.4)	0.159		
40-49	1.4 (0.8 – 2.5)	0.285		
50-59	0.8 (0.3 – 2.2)	0.692		
>60	1.6 (0.5 – 5.9)	0.451		
HIV				
Unknown	1	-	1	-
Positive	**2.1 (1.4 – 3.3)**	**0.001**	**2.4 (1.3 – 4.5)**	**0.007**
Contact details				
Not recorded	1	-	1	-
Recorded	**2.4 (1.6 – 3.5)**	**0.000**	1.6 (0.9 – 2.6)	0.090

Factors associated with long waiting time

The univariate analysis presented in Table 3.9 revealed sub-district and referral hospital to be associated with longer lag times between Pap smear and colposcopy attendance. Health authority, age, HIV status and recording of contact details showed no association with duration of time to attendance of appointment. Patients from sub-district C had the shortest waiting times. Compared to Chris Hani Baragwanath Hospital, the other hospitals had 2.1 to 3.8 months shorter waiting times (p<0.006).

On multivariate analysis, sub-district was dropped due to colinearity with referral hospital (as previously discussed), and only the hospital to which a woman with a high grade lesion was referred, remained a significant predictor of time to colposcopy attendance (Table 3.9).

Table 3.9 Predictors of waiting time from Pap smear to colposcopy

	Univariate Analysis		Multivariate Analysis	
	coeff (95% CI) difference (mo)	**p value**	**coeff (95% CI) difference (mo)**	**p value**
Health Authority				
LG	1	-		
NGO	-0.8 (-1.9 – 0.3)	0.161		
Provincial	-0.3 (-1.5 – 0.9)	0.667		
Sub-district				
A	1	-		
B	-1.3 (-3.1 – 0.5)	0.144		
C	**-1.8 (-3.1 – -0.5)**	**0.008**		
D	**2.2 (1.0 – 3.5)**	**0.001**		
E	0.3 (-1.0 – 1.6)	0.638		
F	-0.6 (-3.0 – 1.9)	0.640		
G	**3.1 (1.7 – 4.6)**	**0.000**		
Age				
<30	1	-		
30-39	-7.6 (-1.9 – 0.4)	0.206		
40-49	-0.03 (-1.3 – 1.3)	0.964		
50-59	0.4 (-1.8 – 2.6)	0.726		
>60	-0.03 (-3.0 – 2.9)	0.985		
HIV				
Unknown	1	-		
Positive	0.1 (-1.0 – 1.1)	0.888		
Contact details				
Not recorded	1	-		
Recorded	-0.5 (-1.5 – 0.5)	0.294		
Referral Hospital				
CHBH	1	-	1	-
RMH	**-3.2 (-4.2 – -2.2)**	**0.000**	**-3.2 (-4.2 – -2.2)**	**0.000**
EH	**-3.8 (-6.1 – -1.5)**	**0.001**	**-3.8 (-6.1 – -1.5)**	**0.001**
CMJAH	**-2.1 (-3.5 – -0.6)**	**0.005**	**-2.1 (-3.5 – -0.6)**	**0.005**

CHAPTER FOUR

4. DISCUSSION AND LIMITATIONS

4.1 Discussion

In this chapter, the results obtained from the analysis of the study data are discussed and interpreted in light of other published studies.

This study shows that the cumulative cervical screening coverage for the period 2000 to 2008 is below target for both the district (30.7%) and the province (21.4%). A high number of Pap smears continue to be performed in women less than 30 years, who are outside the target age group according to the national policy. Despite this, a relatively significant proportion of high grade lesions and invasive cancers (4.4%) are detected in young women. In evaluating referral to colposcopy, there is a high loss to follow up, with only 28% of women with high grade lesions and invasive cancers detected at Pap smear, attending colposcopy appointments. Long waiting times between Pap smear and colposcopy, up to 15 months, were noted. Differences in practice and procedures between individual clinics, between referral hospitals, as well as between health authorities, contribute to differences within the district in system effectiveness and performance.

4.1.1 Cervical screening coverage

This analysis demonstrated a low cumulative coverage of cervical screening in the Johannesburg Metro District, and in the Gauteng province. By a considerable margin, both the district and the province are not on target to achieve 70% coverage that was planned for the first ten years of the national programme. This finding is supported by

other studies that have revealed low coverage of cytology-based screening programmes in developing countries,[66,67] including South Africa.[51,68,69] It is reported that only 5% of women in developing countries undergo cervical screening compared with 40% to 50% in the developed world.[70] Population-based surveys showed that cervical cancer screening coverage in developing countries is on average 19%, compared to 63% in developed countries, and ranges from 1% in Bangladesh to 73% in Brazil.[71] Considerable inequalities in screening coverage exist across global wealth deciles, while women at the highest risk of developing cervical cancer are among the least likely to be screened. In a cervical screening programme, it is only through ensuring a high coverage rate (over 80%) of the target population, that any benefits will be seen in reduction of incidence and mortality from cervical cancer.[4,5]

However, it is evident that while coverage is well-below target, there does appear to be a sharper increase in more recent years. This is possibly due to increased efforts at improving screening coverage in recent years by the Gauteng Department of Health, following recommendations by a large multicentre study that evaluated the implementation of the programme, and instituted follow-up training for programme and facility staff.[51] Another possible reason is increased funding and prioritisation of cervical screening in the province, evidenced by then-Health Member of the Executive Council (MEC) of the Gauteng Province, Dr Gwen Ramokgopa's announcement of an R8 million budget allocation for cervical screening in 2001/2.[72] It should be borne in mind that if coverage is increased to required levels to meet programme targets, the implications of increasing current levels of screening would necessitate commensurate increases in levels of funding, infrastructure, staffing, and laboratory capacity to be made available.

While this study has presented data to assess the current coverage status, it has not attempted to determine the reasons for the low screening coverage. Other research has attributed low uptake of cervical screening to firstly patient factors including poor public knowledge and awareness of the need for cervical screening.[4,73] Women report lack of family support, fear, anxiety, lack of understanding of the Pap smear test and fatalistic attitudes (not wanting to know if one has cancer).[4,73]

Secondly, there are health system barriers to accessing preventive health services including health workers attitudes and practices,[51,52,74] and programmatic challenges.[42,49] In South Africa, there is a shortage of clinic staff,[75] and nurses report reluctance to offer Pap smears for fear of increasing their workloads.[13,51] Many nurses disagree with the policy recommendation on the screening interval and target age for screening. In one study, 84% of nurses were opposed to the 10-year policy as they believed cancer could develop during the screening interval. The vast majority interviewed felt that screening should occur every three to five years, starting before age 30.[8] After an intervention involving training and explanation of the rationale for the policy, nurses' ability and willingness to provide screening increased. This resulted in an increase in coverage and an increase in the proportion of smears done in the target age group.[8] This highlights the need for interventions to address quality concerns, knowledge, skills, attitudes and willingness to provide services.[10]

Some authors have attributed the low testing rates in some countries that use cytological screening to poor programmatic quality and lack of programme management skills.[42,49,66,76] Even in the United Kingdom, a developed country, prior

to introduction of an organised national programme, the cervical cancer screening system was ineffective due mainly to organisational problems. Most cytological tests had been performed opportunistically on women presenting for gynaecological consultation. At least two-thirds of women with invasive cervical cancer had never been screened, and more than 90% of women over 40 years of age had never been screened.[77]

The concept of "informed uptake" is gaining acceptance worldwide- achieving high uptake rates while ensuring that patients are making informed choices and are aware of all the risks and benefits of participation.[78] Some interventions that have been shown to improve coverage include personal invitation letters, but these are noted to be difficult to implement in low-resource setting..[4,78] Community strategies have been employed to varying success.[79,80] In some settings a multimodal combination of community health worker (CHW) outreach and media exposure produced large increases in Pap testing.[74,81] Media-based campaigns can produce short-term and geographically specific increases in uptake, but evidence for their effectiveness in leading to sustained increases is varied.[4] Inclusion of cancer-related material in popular television series has shown pronounced short-term effects on screening uptake.[78] Efforts aimed at client recruitment within the health facilities and from the communities, as well as mass awareness campaigns using the media, have been effective in bringing women into the clinics to have Pap smears.[79]

Variation in coverage in Gauteng Province

Marked variation was noted in screening coverage between the districts in the Gauteng Province as well as between the sub-districts in the Johannesburg Metro

District. From the provincial comparison, Johannesburg Metro District performs significantly better than the other districts, with Tshwane, West Rand and Metsweding having very low cumulative screening coverage. These variations are concerning and may suggest continuing inequity in delivery of cervical screening services. A study in the mid-1990s in the Western Cape, South Africa, showed inequity in screening practices for different age groups as well as for geographical settings, with metropolitan areas having higher screening rates.[82] Research suggests that women living in urban areas are more likely to attend for screening.[4] Other reviews elsewhere have noted that cancer screening is underutilised by ethnic minorities, persons living in rural areas, the poor, the uninsured, and the elderly.[56] In this study, the low coverage in Metsweding and West Rand could be explained by the fact that large parts of these districts are rural, but the low coverage in Tshwane is difficult to understand as it is a large, metropolitan district.

The District Health Barometer presents a valuable comparison across the districts in South Africa on a wide range of indicators. The finding of better cervical screening coverage by JMD compared to other districts, is consistent with other indicators showing this district to maintain superior performance with relation to TB cure rates and immunisation coverage, and lower incidences of diarrhoeal disease and children under five not gaining weight.[63] JMD belongs to the top socio-economic quintile and amongst least deprived districts that generally demonstrate better health outcomes.[63] There are numerous possible reasons, as a district requires adequate budgetary allocation, sufficient human and other resources, efficient management, and good systems in place to function smoothly. According to the District Health Barometer, JMD is ranked tenth of 52 districts nationally, in terms of non-hospital primary health

care spending, well above the national average.[63] Historically, the larger metropolitan districts have benefited from better staffing and budgets than other districts, and although these differentials are being narrowed, it is still fair to say that a large, highly populated urban district like JMD, which is well-served in terms of health facilities and resources, may have better service outcomes than other districts even within the province. It is unsure why Tshwane should be among the poorer performing districts in the province. It is a metropolitan district in socio-economic quintile four, performs relatively well on PHC expenditure, [63] and has a greater supply of health facilities and human resources available than the smaller districts in the province. Tshwane also performs poorly in PHC utilisation rate, antenatal HIV testing, and stillbirth and perinatal mortality rate.[63]

Another factor that may explain differences between districts is the differences there may be in management style. Very often, a champion manager who prioritises a certain programme may see results of better performance in that selected programme. Other programmes (e.g. TB, HIV, etc) have reported similar differences between districts which have been ascribed to better and more innovative management and leadership by an internal change agent who becomes an "early adopter".[83]

There were also differences in coverage between the sub-districts in JMD, ranging from a low of 22% (sub-district E) to highs of 44% (sub-district C) and 48% (sub-district A). Sub-districts A and C have more local government clinics. There could be differences in management style, staffing and programmatic practice, between local government and provincial-run clinics and also at sub-district level. Historically, preventive services were core to municipal health functions, and these clinics also had

a higher attendance of young females who attended for family planning services. It may be that these historical differences still persist, resulting in higher screening rates in LG compared to provincial clinics.

Clinics that perform higher volumes of screening Pap smears are likely to pick up a higher proportion of abnormalities. Increased levels of screening in an unscreened population, leads to higher rates of abnormalities detected.

Individual clinic practices contribute significantly to their performance in respect of smears performed. Some anecdotal findings from the data collection efforts support the assertion that champion managers at facility level have the potential to positively influence screening coverage. The clinic that held screening drives and the ones that use monthly targets are able to increase the numbers of Pap smears performed beyond what is routinely achievable.

4.1.2 Screening in women less than 30 years

This study demonstrated that each year, over 20% of the total Pap smears recorded in the district, are done on women less than 30 years of age, despite the national policy stating that screening should target women over the age of 30 years. This finding has also been observed in other studies in South Africa.[8,13,51,54] It is suggested that this may be due to healthcare workers' lack of knowledge and acceptance of the policy, even after training.[51] In many countries, paradoxically, coverage rates decline with advancing age, when cervical cancer incidence rates are the highest.[71] In this study, many facilities primarily targeted women attending family planning clinics or HIV

positive women starting ART for cervical screening, and therefore did large numbers of smears on young women neglecting higher risk older women.

The national cervical screening policy recommends screening in women 30 years and older. Studies have clearly shown that cytological screening in women aged 20-34 years is less effective at preventing invasive cervical cancer than it is in older women.[84,85] Also, extending screening to younger age groups would result in a greater amount of low-grade disease detected and hence, a larger number of women made anxious,[86] and importantly for the health system, an increase in excessive colposcopy referral.[87]

In line with WHO recommendation, the South African national policy was a rational attempt to ensure high coverage of the high risk target age group, by decreasing the frequency of smears. By continuing to do a large number of smears on relatively low-risk younger women, resources are diverted from the actual target population for the screening programme.

Most recent International Agency for Cancer Research (IARC)[4] and WHO[5] recommendations state that new programmes should start screening women aged 30 years or more, and include younger women only when the higher-risk group has been covered. Existing organised programmes should not include women less than 25 years of age in their target populations, and if a woman can be screened only once in her lifetime, the best age is between 35 and 45 years. Age is the most important risk factor for cervical cancer and screening should aim to target high-risk women.[4]

Interestingly, despite a clear policy in place that addresses this, debates are still ongoing on the optimal age to initiate cervical screening, and a senior manager in the Gauteng Department of Health's Mother and Child Directorate, has stated recently that the province intends dropping the age at which screening should commence to 25 years.[88]

However, this is contradictory to expert opinion, that argues for countries to first scale up coverage in the high risk older age groups, before extending to younger women and increasing the frequency of Pap smears.[4,5] It is a concern that targets in South Africa are not being met for the current age groups to be screened, so dropping the age at which to begin screening would serve only to strain the programme even further. The resultant increase in the burden on the health system and the laboratories, if a hugely increased volume of smears would need to be done, has not been estimated. It is necessary to first address the reasons for not achieving current screening coverage targets, including health workers practices and uptake of services. In addition, it should not be forgotten that cervical screening prevention is about more than just doing Pap smears and also requires effective management and treatment of high grade lesions.

4.1.3 Screening in HIV positive women

This study found that 20% of women in whom high grade lesions were detected, were documented as being HIV positive. Other studies have also shown an almost 6 times higher risk of showing HSIL on Pap smear in HIV infected women.[23] South African studies have found an exceptionally high prevalence of cervical abnormalities in HIV positive women of up to 66%,[89] especially in women less than 30 years.[27] In keeping

with other studies,[23] and notwithstanding limitations of the data, our study also showed that women with high grade lesions who were HIV positive were on average younger than those in whom HIV status was unknown.

Another observation when conducting this study was that some clinics were doing Pap smears almost exclusively on HIV positive women for pre-screening prior to initiation of ART. These facilities were conducting little or no general screening for cervical cancer in high risk older age groups.

The high prevalence of cervical abnormalities in HIV positive women has major health planning and resource implications, particularly as coverage of ART increases in South Africa.[89] Theoretically, cervical cancer prevention services should be integrated within the platform of HIV/AIDS care and treatment programmes in countries like South Africa, which have a dual burden of HIV and cervical cancer.[90] Women who are screened and found to have SILs should also be offered HIV voluntary counselling and testing.[23]

The current practice in HIV/AIDS clinical management is for annual screening of HIV-positive women who are immune compromised (CD4 <350).[9] A serious gap exists in the national cervical screening policy and guidelines, as it does not explicitly address the issue of screening in HIV positive women.[91] The IARC reports that HIV-positive women may benefit from more frequent screening than HIV-negative women, but that the issue of beginning screening at a younger age in HIV-positive women is unclear and requires study.[4] The Centers for Disease Control and Prevention (CDC) recommends that in developed countries, HIV positive women be

screened for SILs more frequently than HIV negative women, having two cytological assessments within the first year after HIV diagnosis and annually thereafter, with referral for colposcopy for any smear showing an ASCUS or more severe lesion.[92] The WHO recommends that screening criteria for women with known HIV infection should be developed at the national level with these issues in mind.[5] Cytology screening is equally effective in HIV-positive and HIV-negative women.

If South Africa were to adopt such policies given the high HIV prevalence, the resultant burden on the health services would need to be considered, and intense preparation would be obligatory in order to cope, given the challenges with the current strategy. While the practice of conducting more intensive cervical screening for HIV positive women may be justified based on current literature, this should be complementary and not at the expense of the routine screening programme. The main objective of the cervical screening programme, even in a setting of high HIV prevalence, remains high coverage. While the practice of cervical screening is explicit in the policies of the HIV and AIDS directorate at provincial level, there are no concrete guidelines as to the frequency and timing of Pap smears in either the national cervical screening guidelines, or the National Strategic Plan related to HIV/AIDS care. There is some evidence that now makes it imperative to clarify issues related to cervical screening in HIV positive women in the national guidelines.

4.1.4 Abnormal smears in young women

In this study, the analysis of abnormal smears recorded in the district, showed that low grade lesions were more commonly found than high grade lesions, especially in younger women; and the proportion of HSIL and cancers increased in older women.

This is consistent with current understanding of the natural history of the disease of a clear relationship between age and LSIL, with younger women having a high rate of LSIL which decreased with increasing age.[17] A similar but inverse relationship between age and invasive cancer is described with the rate being low in young women and increasing with increasing age. Research in South Africa showed that the prevalence of precursor SILs was highest in women in their late thirties.[93] The proportion of abnormal smears decreases with age, but abnormalities among older women have a much greater chance of leading to true malignancy.[94]

Findings of this study reveal that 11.7% of the total smears done in all age groups in 2008 were abnormal (including low grade and high grade lesions). This exceeds findings on smear abnormality in other studies, even in developing countries. For example, in a Brazilian study, 5.4% of Pap smears were abnormal and this was attributed to inadequate previous screening.[80] In countries where the female population is screened appropriately, it has been estimated that less than 1% of Pap smears should harbour a cytological abnormality.[58] The high rates of Pap smear abnormality detected in this study, raises the question of health system capacity for follow-up and referral and treatment facilities. If South Africa were to achieve screening targets, would the country cope with the resultant demand for colposcopic treatment services?

In the evaluation of referral in sampled clinics, 21% of women with high grade lesions that required referral for colposcopy were younger than 30 years. The screening data also revealed that 4.4% of the total Pap smears done in women less than 30 years, revealed HSILs and cancers. This is higher than studies in developed

countries which show that high grade cytological abnormalities are diagnosed in about 1.4% of young women screened, although this was for women under the age of 25.[94] In a population-based South African study of prevalence of cervical abnormalities in the 1990s, 1.5% of women less than 30 years were found to have HSIL and invasive cancer.[17] The WHO guidelines however state that in a previously unscreened population of women aged between 25 and 65 years, 1 – 4% of HSIL are likely.[5]

Even though this study was not population-based and relied on healthy women presenting at health facilities for Pap smears, and may have included large numbers of HIV positive women receiving pre-treatment screening, these results suggest that there may be an increased risk of high grade cervical intraepithelial lesions in young South African women. One may infer that this is due to the high prevalence of HIV, especially in females in the age group 15 – 24 years, as cervical dysplasia is recognised as an HIV-related condition. However, this may also be ascribed to the sexual behaviour and practices of South African men and women, including young age at sexual debut, which results in high prevalence of HPV infection in young South African women and younger ages at which pre-cancerous lesions develop.

While the WHO and IARC do recommend commencing cervical screening at 25 years of age where resources permit, they also suggest a rational approach to policy setting, with the initial focus on high coverage in high risk age groups, then expanding to younger groups and more frequent screening.[4,5] In light of this, the debate in South Africa should still revolve around improving coverage with the current policy, before changing the age limits for initiating cervical screening. There is evidence to suggest

that while maintaining the current guidelines for cervical screening of the general population, there needs to be clear policy for screening HIV positive women at younger ages, with higher frequency.

4.1.5 Pap smear adequacy

In this study, we found below acceptable smear adequacy in six out of fourteen clinics sampled. Pap smear inadequacy was also demonstrated to be poor in other studies set in South Africa.[13,51] In one study, more than 40% of smears taken in a district of the Western Cape were not satisfactory, and in many of the smears endocervical cells were absent.[13] This was as a result of poor technique in performing the smear, where the endocervical junction was not sampled.

Poor quality Pap smears reduce the cost-effectiveness of cytological cervical screening, as it necessitates repeated smears being performed. Also, smears taken without endocervical elements reduce the chance of detecting cervical atypia because the squamocolumnar junction is not sampled.[95] In various studies, a large proportion of women who developed cervical carcinoma had had smears four to five years prior to diagnosis that were correctly interpreted as normal, but lacked endocervical elements.[96,97] This suggests that the cancer might have been detected earlier had the smears contained endocervical elements. These studies found that Pap smears with no endocervical elements present had a high percentage of false-negative results.

It was not determined in this study, whether there was a quality assurance system in place for routine monitoring of smear adequacy rates. While each Pap smear result received by the clinic has a comment on smear adequacy, clinic managers do not

routinely receive regular reports on the smear adequacy for the facility. The NHLS are not able to easily compile a summary of adequacy rates for all clinics due to the challenges associated with the cytology reporting format. The coding system for Pap smear results is based on multiple lines of text entry and the electronic database is not coded uniformly for adequacy. If the laboratory does not communicate this information routinely to the district, sub-district and facility managers, it is unlikely that the issue of smear quality is regularly addressed. However, facility managers may be proactive and regularly monitor smear adequacy for their staff to address any need for re-training on technique.

According to the National Guidelines, if the smear adequacy rate for a facility falls below 70%, immediate action is required in the form of re-training and refresher courses for facility staff. It is assumed that this would be the responsibility of the NHLS to report, and programme and sub-district managers to act on. These systems are not currently in place in the Johannesburg Metro District, but a formal procedure is necessary to address this.

Limited adequacy is almost completely due to poor sampling. This is primarily attributed to inadequate training of nurses performing smears, which can easily be addressed through education in sampling technique.[13] High quality of Pap smears is especially important in low-resource settings, where women may undergo screening only once or twice in their lifetime.[4]

4.1.6 Loss to follow up

An important finding in this study was the high proportion of women who have had a Pap smear who are lost to follow-up through the referral process. In the present study, the Johannesburg Metro District performed poorly on system effectiveness and performance measures, as the notification rate was 57%, referral appointment rate was 38% and the appointment compliance rate was 28%. This means that out of 557 women with high grade lesions and cancers, only 318 received results and referral, 211 made appointments at colposcopy units, and only 155 attended their appointments. There was a consistent finding of poor system effectiveness and performance across most clinics in the study, irrespective of health authority or sub-district. The reasons for women not receiving their results, not making appointments at colposcopy clinics, or not attending colposcopy appointments, would be valuable to know, but were beyond the scope of this study to determine.

A high level of attendance for screening is necessary but not sufficient to ensure a successful cervical cancer screening programme. Screened women with abnormal tests must also receive appropriate treatment. Rates of colposcopy attendance vary enormously across settings and populations. A recent systematic review described a 10% to 40% rate of nonadherence.[56] In low resource settings, levels of loss to follow-up in cervical cancer screening programmes were as high as 70%,[36] while one study in Peru found 77% of women with positive cytology did not have diagnostic investigations and treatment as required.[98] In low-income minority women in a developed country, on any single clinic day, an average of 39% of appointments were no-shows.[65] In South Africa, a study in the 1980s showed that 70% of women with abnormal smears did not attend colposcopy,[53] whereas a more recent study estimated

colposcopy non-adherence as 50%.[8] However, a South African study recorded a 10% non-adherence rate post screening, albeit in a research setting, with substantial focus placed on collecting contact details and tracing defaulters.[99]

Non-adherence to referral is consistently cited as a significant problem in cytological screening programmes, and is thought to drive down the effectiveness of screening programmes regardless of which screening modality is used.[36] Loss to follow-up has also been implicated as a contributing factor to adverse outcomes in retrospective analyses of advanced cervical disease.[56]

Loss to follow-up in the cytological screening programme is cited as a reason to suggest using other modalities for screening, viz. VIA and DNA HPV testing. "See and treat" methods may be good alternatives because they obviate the need for multiple facility visits, but these strategies also have their disadvantages and are not recommended for routine implementation in resource-poor settings at this point.[5] Some believe that South Africa does have the infrastructure and resources to deliver a cytological screening programme effectively while others attributed challenges with cytological screening to poor programmatic quality and lack of management skills, rather than to technological limitations of the Pap smear test.[42,49,66,76] It is said that the recent intense focus on other screening methods is undermining improvements to the current cytologic strategy. It is not necessary to debate the technology to be used, but rather to act through a systems approach focused on programmatic quality, and work to improve the current programme.[49]

The WHO recommends that to ensure that women with an abnormal screening test can be reached for follow-up, the woman's contact details should be noted at the time of screening and she should be counselled on the importance of coming back for results and follow-up care.[5] In addition, the clinic should keep a directory of all women with abnormal test results, indicating whether they have received the results and been followed up, and designate someone to ensure that follow-up is done. For women who do not return for follow-up, providers can send a letter by mail, telephone women at home or at work, or ask CHWs to contact women directly at home.

Despite the importance of assuring good levels of compliance with follow-up, most interventions for improving the cervical screening programme have focused on increasing attendance in screening programmes. For example, in a Cochrane Review of strategies to improve cervical cancer screening attendance, only three of the selected 35 studies were about compliance with follow-up after screening.[100]

4.1.7 Factors associated with colposcopy attendance

The health service factors associated with colposcopy attendance in this study included the health authority, and hospital women were referred to. Women referred from NGO-run clinics, and those from sub-districts E and F who were referred exclusively to CMJAH and EH, were less likely to attend colposcopy appointments than those from other health authorities and sub-districts. With regards to the NGO-run clinics, the concern is that being outside the scope of government authority, referral processes may be not as well-defined as they are from provincial and local government clinics. Practices at the CMJAH and EH may explain why women were less likely to attend colposcopy. Perhaps it is related to the fact that women make their

own appointments at these hospitals, compared to CHBH, where appointments are routinely made for women by the referring clinic staff. Thus at CHBH, women were found to be more likely to attend the appointments, even though they had a longer waiting time for appointments.

The literature cites a number of reasons for non-adherence to colposcopy appointments, including patient and health system factors. Some patient factors that negatively influenced care-seeking behaviour in this respect include lack of understanding of the purpose of colposcopy, fear and emotional consequences of abnormal Pap smears, forgetting appointments, the severity of disease and a woman's perception of risk.[56,65] Younger age, minority ethnicity, lower education level, and lower grade abnormalities on Pap smears tend to be associated with decreased adherence to referral advice and compliance to treatment.[56]

Health system barriers for adherence include distance, availability and access to the referral centre.[98,101] A lack of understanding of the steps in the referral process, as well as poor rapport or communication with the provider results in many women failing to attend for results or further treatment.[65,102]

This study did not set out to determine clients' reasons for not attending appointments, but age and HIV were evaluated as possible factors associated with colposcopy attendance. There was no association between clients' age and attendance of colposcopy appointment. A similar finding was reported in a Western Cape study where adherence to referral recommendations did not differ with age.[13]

In women who had high grade lesions, those who were HIV positive were 2.4 times more likely to attend appointments than those in whom HIV status was unknown. An assumption can be made that further treatment for these women was dependent on them completing ART pre-screening protocols. It seems likely that these were women who were being referred from ART-rollout sites, so they were in essence "in the system" and were more likely to comply with referral processes. These women were also most likely recipients of intensive counselling as a result of their HIV diagnosis and possible commencement of ART. The health messages they were likely to receive would positively influence their health-seeking behaviours. Another study conversely found higher rate of loss to follow-up in HIV positive women.[103]

Provider behaviour is known to have an effect on referral of women with high grade lesions.[13,51] Health services in this study did not have processes in place for call and recall of clients after Pap smears were done, and this may in part account for the high loss to follow-up observed. In this study, not all women had contact details recorded in the Pap registers; however, women whose contact telephone numbers were recorded were more likely to attend appointments, although this association was not significant in the multivariate analysis. If a woman did not attend her appointment to receive the Pap smear result, the clinic would have no way of contacting her, and especially of referring her to colposcopy in the event of an abnormality requiring further investigation and management. Of more concern, the colposcopy appointment registers do not reflect any contact details- so if a woman did have a Pap smear at her local clinic; did return and was given her result; did make an appointment for colposcopy; but failed to attend that appointment; she was essentially lost to the system. Furthermore, the colposcopy clinic at each hospital does not call clients who

failed to attend an appointment to reschedule. This reflects a serious weakness in the cervical screening programme, as high loss to follow-up reduces the cost-effectiveness of this screening method and will hamper efforts to decrease disease incidence and mortality.

In many developed countries, personal health information systems enable easy identification of women who fail to attend follow-up appointments. The lack of these systems in developing country settings such as Brazil, have made it very difficult to implement call and recall systems.[42] A study in Peru suggests a system to record details of screening dates, results and treatments to be kept by the women and taken from visit to visit, as a means of improving screening and referral.[98] In South Africa, it has been suggested that a woman's health card could be used as a continuous record of care, which would provide a link between screening information and colposcopy data.[51]

Interventions to improve adherence employ a broad range of methods focusing on systemic/structural and behavioural contributors, and have achieved varying success.[104] A systems intervention in the Netherlands appeared to be effective in improving client adherence to follow-up recommendations. The quality improvement interventions included utilising computerised patient information recording system, delegation of clinical tasks to practice assistants, provision of outreach support to trace defaulters and issuing of reminder letters.[105]

Among the most effective behavioural strategies to improve referral adherence are personalised reminders to patients by healthcare workers.[98] Appointment reminder

systems are being employed in developing country settings such as Zambia, involving text messages to remind patients of appointments, telephone calls to re-schedule missed appointments, and if these fail, lay health worker follow-up at the patient's home.[36]

The opportunities for innovation in use of mobile technology in delivering information, mass communication and service delivery are enormous. Cellular phones should be systematically used for tracing patients in the cervical screening programme who require referral, especially in a country like South Africa with high cellular phone penetration.[73,79]

The use of CHWs should also be explored, in reaching areas with poorer access to communication lines. Local agents have the advantages of shared culture, class and language which can promote understanding, even among women with low educational background.[97] In many developing countries, successful follow-up of women with abnormal screening tests has been achieved by using dedicated personnel to re-contact these women. Improvements in follow-up of between 89% and 100% have been documented from studies in Cameroon, China, Costa Rica, South Africa, Venezuela Vietnam and Zimbabwe.[49] Use of CHWs was also found to be cost-effective in studies in the Western Cape, South Africa.[36]

Another factor related to poor attendance of appointments in this study, is the long lag time between Pap smear and colposcopy attendance. In a study in the Western Cape, adherence to recommendations for a follow-up Pap smear were significantly lower for women who were asked to return at 12 months compared to those who had to return

for follow-up at 6 months.[13] In this study, it was found that clients had to wait as long as 15 months for attending a colposcopy appointment. In the Gauteng Province and nationally, even for other non-emergency health services provided at higher levels of care, e.g. surgery for cataracts and tonsillectomies, there are significant waiting times.[106] This is due to the huge catchment populations causing large patient loads at public hospitals, and also the lack of services being available at district level.

It is not known from this study why there were long lag times between Pap smears and colposcopy attendance. One reason could be the limited availability of colposcopy services at referral hospitals in South Africa.[9] Insufficient numbers of colposcopy clinics to serve the population size and a shortage of human resources result in an inadequate supply of colposcopy services. Colposcopy services are only provided at three facilities within the JMD, a district that conducted over 60,000 Pap smears in 2007/8.[60] Each of these three colposcopy units are functioning at near-maximal capacity, and have had to provide services to the 3 154 women with pre-cancerous and cancerous lesions in 2008 that required colposcopy. It is possible that colposcopy services have not been extended within the district due to equipment and personnel constraints. This shortfall in colposcopy services requires primary attention to improve programme effectiveness. An article on the estimated human resource requirements for introducing a cervical cancer screening programme in South Africa, suggested that every regional hospital in the country would be required to create and run a weekly colposcopy clinic in order to achieve coverage goals.[107] A recent strategy in Scotland to establish a colposcopy service at the family planning centre provided more rapid access to colposcopy, and avoided long waiting times that patients normally endured at the specialist hospital.[108] The authors argue that as long

as there are close working links with the hospital centre, large referring clinics can establish a successful colposcopy service.

From the findings of this study, various health system-related factors have been identified that may be responsible for poor attendance of colposcopy services by women with high grade lesions. This study suggests that the poor system effectiveness and performance relate to practices and processes at the clinics and the referral hospitals, and include issues of record keeping, procedures for making colposcopy appointments, and capacity at the referral colposcopy services.

Without efficient diagnostic services and therapy, screening would hardly be justifiable.[109] Screening by itself will not prevent a single case of cervical cancer. An effective system for follow-up and treatment of women who test positive is perhaps the most important component of a successful cervical cancer prevention programme. This would require the underlying systemic issues of staffing, training and infrastructure to be addressed. To provide an effective screening programme ultimately would necessitate a functional health system.[10]

4.1.8 Challenges in monitoring the cervical screening programme

While this study highlighted serious challenges in implementing the cervical screening programme, it also revealed constraints with available cervical screening data, a valuable finding in itself. There are various limitations with the data that is used to monitor the programme, including primary data collected on the numbers of screening Pap smears done (numerator) and also the assumptions used in determining target populations (denominator) when calculating coverage.

In determining the number of screening Pap smears done, this study relied on existing routinely collected data at the facilities. The validity, reliability and completeness of these registers cannot be guaranteed. It is unsure whether all staff completing monthly collation sheets have the correct understanding of the criteria for screening Pap smears, which are used to determine screening coverage. If, for instance, diagnostic Pap smears, those done for HIV positive women or for women outside the target age groups, are included in the figures reported in the DHIS, this would overestimate the screening coverage. Furthermore, it cannot be excluded that multiple Pap smears may have been done for the same individual in one year, which would overestimate coverage.

The target population of women over 30 years of age is derived from census data. There are some assumptions made with regards to the reprocessing of census data for derivation of population estimates. Stats SA publishes national and provincial population estimates annually, based on the census, the most recent having been conducted in 2001. Projections are made for national and provincial populations, using various methodologies.[110] A comparison shows that the projected 1996 population figures were about 1,2 million higher than the published 1996 Census, while a very small difference can be found between the published 2001 Census and this projection on that date. The DHIS uses this data to prepare projections at district and sub district level through an iteration process using estimated birth, death and net migration data. There have been numerous problems reported with the Spectrum model software used by Stats SA to derive estimates of the population size.[111]

Also, the data collected by the DHIS reflects Pap smears done in all public sector facilities, yet the denominator (catchment population) includes all women, insured and uninsured. Including insured women in the denominator, who most likely have had Pap smears in the private sector which is not reflected in the numerator, may underestimate the screening coverage.

It is important to address these data challenges, as effective monitoring of the cervical screening programme is essential to its successful implementation.

4.2 Limitations

The study relies on existing data collected and recorded in registers at the facilities, in order to identify women who have high grade lesions found on Pap smear, and then to trace whether they have attended colposcopy. The data analysed in this study depends on the quality and consistency of these existing data and records at the facility level, and therefore would result in incorrect estimates of referral, adherence and other indicators where data may not be accurate or complete. However, every effort was made to utilise multiple data sources when possible to minimise this limitation.

The sample of clinics was chosen to be representative of the entire district. However, the results may not be generalised to other districts or provinces in the country, as the strength of the cervical screening programme and health institutions' capacity to implement the service may differ vastly in other settings. Johannesburg Metro District is known to be better-served with healthcare facilities, human resources and referral

sites. However, the trends and system challenges highlighted here may also be applicable to other districts in South Africa.

In using data recorded on HIV status, it is acknowledged that this information was not systematically collected or recorded for all patients. This kind of opportunistic data is therefore only used to demonstrate the differences between clinics that were screening only HIV positive patients versus those that were conducting general screening of the target age group. As far as possible, no inferences were drawn regarding HIV status due to the bias in collection of this data.

Despite the issues related to limitations of data quality and the data sources, this study still presents valuable and useful information on the cervical screening programme in this setting, and offers an insightful account of the challenges that must be addressed in order to improve the programme, to see declines in rates of disease and death from this disease.

CHAPTER FIVE

5. CONCLUSION AND RECOMMENDATIONS

5.1 Conclusion

This study demonstrated that cervical screening coverage has improved since inception of the programme but still falls short of what is required for achieving the national cervical screening programme goals. The study confirms the many barriers to delivering an effective cervical screening programme that exist in the Johannesburg Metro District, Gauteng Province.

Key challenges demonstrated by this study include low screening coverage, continued screening targeted to young women outside the target age groups, poor Pap smear adequacy, and inadequate referral of women with high grade lesions and cancers for diagnosis and treatment. Some of the reasons for the poor system effectiveness and performance relate to provider practices, record keeping, and referral processes.

Addressing these challenges is important to improve the effectiveness of the programme. Only by reorganising and improving implementation of the current programme, will the impact on cervical cancer incidence and mortality be seen.

If South Africa is to reorganise the ineffective current national cervical screening programme, it would require strong political commitment, translated to well-implemented services, establishing a trained and motivated health workforce, improving the organisation of services, and strengthening its health system.[43]

5.2 Recommendations

The WHO recommends that in developing countries, existing ineffective cervical screening programmes should be urgently reorganised and monitored.[7] It is further said that screening programmes in developing countries can achieve success through strong programme managers who prioritise quality.[112] To decrease incidence and mortality rates from cervical cancer, South Africa must improve implementation of the national cytological cervical screening programme. This requires process improvements in all areas, especially increasing screening coverage of target age-groups and effective referral and treatment of women with high grade lesions. It may also require a detailed look at practices with regard to screening in younger age groups and HIV positive women.

1. Improve cervical screening coverage

A cervical screening programme must achieve high screening coverage over 80% to impact on cervical cancer outcomes.[5] The JMD should look into reasons for low coverage and then focus its efforts on strategies known to improve coverage:

1.1. Raise community awareness

This may involve a variety of strategies, including mass awareness campaigns using the media, e.g. billboards, newspaper articles, advertisements, radio-spots, photo-comics, and features in health educational programmes on television (Soul City). To be effective, these interventions require high coverage.

1.2. Improve client recruitment

This involves training of healthcare workers to "accept" the policy. Staff would be encouraged to opportunistically recruit women in the target age group who may be attending the clinic for other reasons, ensuring that there are no missed opportunities and that all women in the target age group who have contact with the health system are reached. Women should not be recruited only from the family planning clinic or ART programme as is often done, as this will not allow for screening in women beyond the reproductive age. Also, Pap smears should be done on the same day that the woman is recruited at the clinic. Peer educators and of nurses should be trained in order to improve awareness and increase referral of HIV positive women for screening tests.[113]

1.3. Set monthly targets

Clinics that set monthly targets were generally found to maintain higher screening coverage. Instead of using a fixed number per clinic, these targets should be decided by a formula based on estimates of the clinic catchment population, or facility utilisation. One local study found that a quota system in one health district of twenty smears per month per health facility, actually limited the number of smears that should have been done in that population.[75]

1.4. Hold screening "drives"

The GDoH should consider as a strategy, implementing the innovative example set by one clinic that organised a one-day cervical screening drive. It may be more cost-effective to concentrate resources on raising community awareness for a screening

campaign to be held on a specified day. However, there is no evidence that such "drives" would lead to sustained increases in coverage.

1.5. Improve smear adequacy

As per the national guidelines, the province should develop a protocol for monitoring smear adequacy across all facilities. The NHLS should be engaged, and requested to provide programme and sub-district managers with routine monthly reports of facility adequacy data. This information should be regularly fed-back to the facilities, and re-training and refresher courses held for all clinics that fall below the 70% adequacy mark.

2. Ensure referral and treatment of women with high grade lesions

Ensuring treatment of abnormal Pap smears is a challenge, but unless referral and access to colposcopy services is improved, increasing screening coverage will not have an impact on decreasing cervical cancer rates. Some health service issues that should be addressed include:

2.1. Improve referral system

It is important to address the failure of the referral system with regards to cervical screening. Providers should consistently refer women for colposcopy when indicated, and this can be improved through training and continuous reinforcement of the guidelines. As some clinics, hospitals, sub districts and health authorities were demonstrated in this study to perform better, it would be important to adopt best practices and ensure standardisation of referral practices throughout the district.

2.2. Improve data recording and management

Ensure that contact details for all women at screening and colposcopy services are recorded, and that staff have access to communication systems to contact women for re-call. By recording contact details in Pap register and colposcopy appointment registers, and employing a woman's health card, we would be better able to track women through the referral system and recall them if they have failed to attend colposcopy appointments.

2.3. Improve client adherence

Strategies that could be explored include increasing patient awareness and counselling, physical or economic barrier reduction, and health service interventions to trace women who default. The introduction of various reminder systems using motivational pamphlets, explanatory informational brochures, telephone (SMS) reminders, and the use of CHWs have proven to be effective in other settings.[56] Increasing understanding about screening is the first step as women who do not understand why they are being screened are less likely to return for results and possible further treatment.[114]

2.4. Increase availability of colposcopy services

This study suggests a need for more colposcopy services in the district. It is unlikely that the facilities that currently have colposcopy units will be able to increase their capacity, but this should be explored. The province should urgently consider extending the colposcopy services to other hospitals, e.g. South Rand Hospital, and possibly to community health centres (CHCs). This would decrease waiting times and

possibly increase attendance of colposcopy appointments. If there are more referral centres available, the ideal would be to strive for a same-day service, to avoid further losses to follow-up of women who make, but do not attend colposcopy appointments.

3. National review of current cervical screening practices

It is necessary to achieve uniformity and standardisation of practice with regard to age at which screening is initiated and screening in HIV positive women.

3.1. Clarify appropriate age to initiate screening

Many providers do Pap smears on women under 30 years as they do not understand or agree with the current policy.[51] In light of conflicting opinion and practices currently, it would be prudent to hold expert consensus meetings, which would inform and clarify national policy and set uniform screening practices.

3.2. Formalise policy on cervical screening in HIV positive women

The practice of screening only HIV positive women that has been observed at many health facilities must be addressed. The national cervical screening policy of 2000 was formulated before the link between HIV and cervical cancer was firmly established, and does not address the issue of cervical screening in HIV positive women.[91] The current cervical screening policy should be expanded to specifically include guidelines on initiation and frequency of screening in HIV positive women.

5.3 Further Research Areas

1. The reasons for the low screening coverage should be investigated. A study should be done on the knowledge, attitudes and practices of women in JMD regarding the need for cervical screening. A similar study of staff at the clinics providing Pap smears would reveal any reasons to explain poor client recruitment. This would enable programme managers to introduce appropriate interventions aimed at improving the uptake of cervical screening services.

2. In light of some of the differences found in practice between clinics run by different authorities, a study looking at management, processes and resources at the different settings would identify whether these contribute to variations in performance and outcomes between clinics run by provincial, local government and NGO authorities.

3. A study is also warranted to investigate the current status of cervical screening for HIV positive women in the public sector, looking at the age at which screening is initiated and the frequency of screening in this group.

4. It would be important to conduct studies to determine the HSIL treatment rate. This study has only focused on the effectiveness of referral of women with abnormal Pap smears to colposcopy services. It has not, however, explored the subsequent management of these women.

5. A study should be conducted to determine women's reasons for non-adherence to colposcopy clinic appointments.

6. More updated publications on national cancer statistics are vital in order to assess the impact of the cervical screening programme on disease trends.

REFERENCES

1. Ferlay J, Bray F, Pisani P, Parkin DM. GLOBOCAN 2002: Cancer Incidence, Mortality and Prevalence Worldwide IARC CancerBase No. 5. version 2.0, IARCPress, Lyon, 2004.

2. Garcia M, Jemal A, Ward EM, Center MM, Hao Y, et al. Global Cancer Facts & Figures 2007. Atlanta, GA: American Cancer Society, 2007.

3. 2001 National Cancer Registry Tables. CANSA. (Accessed 21 October 2009) Available at: http://www.nhls.ac.za/Cancer%20statistics%20-%202001.pdf

4. IARC. Cervix cancer screening. Lyon: IARC Press, 2005 (IARC Handbooks of Cancer Prevention, Vol. 10).

5. World Health Organization. Comprehensive cervical cancer control: A guide to essential practice. (Accessed 25 September 2006) http://www.who.int/reproductive-health/publications/cervical_cancer_gep/index.htm

6. National Department of Health. National guidelines for cervical cancer screening programme. Pretoria: Department of Health, 2000.

7. Sankaranarayanan R, Budukh AM, Rajkumar R. Effective screening programmes for cervical cancer in low- and middle-income developing countries. Bull World Health Organ 2001; 79(10):954–62.

8. Moodley J, Kawonga M, Bradley J, Hoffman M. Challenges in implementing a cervical screening program in South Africa. Cancer Detection and Prevention 2006; 30:361–368.

9. Denny L. Prevention of Cervical Cancer. In: Ijumba P, Padarath A, editors. South African Health Review 2006. Durban: Health Systems Trust, 2006

10. Kawonga M, Fonn S. Achieving effective cervical screening coverage in South Africa through human resources and health systems development. Reproductive Health Matters 2008;16(32):32–40.

11. Denny L, Sankaranarayanan R. Secondary prevention of cervical cancer. International Journal of Gynecology and Obstetrics 2006; 94(S1):S65-S70.

12. Bradley J, Barone M, Mahe C, Lewis R, Luciani S. Delivering cervical cancer prevention services in low- resource settings. International Journal of Gynecology and Obstetrics 2005; 89:S21-S29.

13. Smith N, Moodley J, Hoffman M. Challenges to cervical cancer screening in the Western Cape Province. South African Medical Journal 2003; 93(1):32–35.

14. Cronje HS, Beyer E. Screening for cervical cancer in an African setting. International Journal of Gynecology and Obstetrics 2007; 98:168–171.

15. Pisani P, Bray F, Parkin DM. Estimates of the world-wide prevalence of cancer for 25 sites in the adult population. Int J Cancer 2002; 97:72–81.

16. Cancer Research UK. CancerStats: Worldwide Cancer. April 2005. (Accessed 21 October 2009).
https://www.givengain.com/cause_data/images/1056/Wolrd_wide_cancer_stats.pdf

17. Fonn S, Bloch B, Mabina M, Carpenter S, Cronje H, et al. Prevalence of pre-cancerous lesions and cervical cancer in South Africa - a multicentre study. S Afr Med J 2002; 92(2):148–56.

18. Mqoqi N, Kellett P, Sitas F, Musa J. Incidence of histologically diagnosed cancer in South Africa, 1998–1999 Johannesburg: National Cancer Registry of South Africa, 2004.

19. Snijders PJ, Steenbergen RD, Heideman DA, Meijer CJ. HPV-mediated cervical carcinogenesis: concepts and clinical implications. J Pathol. 2006; 208:152–164.

20. Blanche BE. Intraepithelial and invasive carcinoma of the cervix in clinical Cytotechnology. Edited by Coleman DV, Chapman PA. London: Butterworths, 1989.

21. Centers for Disease Control. 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. MMWR Recomm Rep 1992; 41:1-19.

22. Clarke B, Chetty R. Postmodern cancer: the role of human immunodeficiency virus in uterine cervical cancer. Mol Pathol 2002; 55(1):19-24.

23. Moodley JR, Hoffman M, Carrara H, Allan BR, Cooper DD, et al. HIV and pre-neoplastic and neoplastic lesions of the cervix in South Africa: a case-control study. BMC Cancer 2006; 6:135.

24. Leroy V, Ladner J, De Clercq A, Meheus A, Nyiraziraje M et al. Cervical dysplasia and HIV type 1 infection in African pregnant women: a cross sectional study, Kigali, Rwanda. The Pregnancy and HIV Study Group (EGE). Sex Transm Infect 1999; 75(2):103-106.

25. La Ruche G, You B, Mensah-Ado I, Bergeron C, Montcho C et al. Human papillomavirus and human immunodeficiency virus infections: relation with cervical dysplasia-neoplasia in African women. Int J Cancer 1998; 76(4):480-486.

26. Lomalisa P, Smith T, Guidozzi F. Human immunodeficiency virus infection and invasive cervical cancer in South Africa. Gynecol Oncol 2000; 77(3):460-3.

27. Gaym A, Mashego M, Kharsany ABM, Walldorf J, Frohlich J et al. High prevalence of abnormal Pap smears among young women co-infected with HIV in rural South Africa– implications for cervical cancer screening policies in high HIV prevalence populations. S Afr Med J 2007; 97:120-123.

28. Stein L, Urban M, O'Connell D, Yu QX, Beral V et al. The spectrum of human immunodeficiency virus-associated cancers in a South African black population: Results from a case–control study, 1995–2004. Int. J. Cancer 2008; 122:2260–2265.

29. Schuman P, Ohmit SE, Klein RS, Duerr A, Cu-Uvin S, et al, for the Epidemiology Research Study (HERS) Group: Longitudinal Study of Cervical Squamous Intraepithelial Lesions in Human Immunodeficiency Virus (HIV)-Seropositive and At-Risk HIV-Seronegative Women. JID 2003; 188:128-136.

30. Massad LS, Ahdieh L, Benning L, Minkoff H, Greenblatt RM et al. Evolution of cervical abnormalities among women with HIV-1: Evidence from surveillance cytology in the Women's Interagency HIV Study. J Acquir Immun Defic Syndr 2001; 27:432-442.

31. Delmas MC, Larsen C, Van Benthem B, Hamers FF, Bergeron C et al, for the European Study Group on Natural History of HIV Infection in Women: Cervical squamous intraepithelial lesions in HIV infected women: prevalence, incidence and regression. AIDS 2000; 14:1775-1784.

32. UNAIDS. Country Progress Indicators. In: Report on the global AIDS epidemic. Geneva: UNAIDS, 2008.

33. Shisana O, Rehle T, Simbayi LC, Zuma K, Jooste S, et al. for the SABSSM III Implementation Team. South African national HIV prevalence, incidence, behaviour and communication survey 2008: A turning tide among teenagers? Cape Town: HSRC Press, 2009.

34. Department of Health. The National HIV and Syphillis Prevalence Survey South Africa. Pretoria: Department of Health, 2007.

35. Franceschi S, Jaffe H. Cervical Cancer Screening of Women Living with HIV Infection: A Must in the Era of Antiretroviral Therapy. Clinical Infectious Diseases 2007; 45:510-3.

36. Goldhaber-Fiebert JD, Denny LE, De Souza M, Wright Jr TC, Kuhn L et al.. The costs of reducing loss to follow-up in South African cervical cancer screening. Cost Effectiveness and Resource Allocation 2005; 3:11.

37. Denny L, Kuhn L, De Souza M, Pollack AE, Dupree W et al. Screen-and-Treat Approaches for Cervical Cancer Prevention in Low-Resource Settings: A Randomized Controlled Trial. JAMA. 2005; 294(17):2173-2181.

38. Goldie SJ, Gaffikin L, Goldhaber-Fiebert JD, Gordillo-Tobar A, Levin C et al. Cost-Effectiveness of Cervical-Cancer Screening in Five Developing Countries. N Engl J Med 2005; 353(20):2158-2168.

39. Ronco G, Rossi PG. New paradigms in cervical cancer prevention: opportunities and risks. BMC Women's Health 2008; 8:23.

40. Suba EJ, Frable WJ, Raab SS. Cost-effectiveness of cervical-cancer screening in developing countries. N Engl J Med. 2006; 354:1535–1536.

41. Summary Chapter: IARC Working Group on Cervical Cancer Screening. In: Screening for Cancer of the Uterine Cervix. Hakama M, Miller AB, Day NE, editors. Lyon: International Agency for Research on Cancer, 1986.

42. Zeferino LC, Pinotti JA, Neves Jorge JP, Westin MCA, Tambascia JK et al. Organization of cervical cancer screening in Campinas and surrounding region, São Paulo State, Brazil. Cad. Saúde Pública 2006; 22(9):1909-1914.

43. Sepulveda C, Prado R. Effective cervical cytology screening programmes in middle-income countries: the Chilean experience. Cancer Detect Prev 2005; 29:405-411.

44. Hoffman M, Cooper D, Carrara H, Rosenberg L, Kelly J, et al. Limited Pap screening associated with reduced risk of cervical cancer in South Africa. International Journal of Epidemiology 2003; 32:573–577.

45. Bailey RS, Selvey CE, Bourne D, Bradshaw D. Trends in cervical cancer mortality in South Africa. International Journal of Epidemiology 1996; 25:488-493.

46. Miller AB. Cervical cancer screening programmes: managerial guidelines. Geneva: World Health Organization, 1992.

47. Cervical Health Implementation Project. Implementing cervical screening in South Africa, vol. I, A guide for programme managers South Africa: University of Cape Town/University of the Witwatersrand: EngenderHealth, 2004.

48. Suba EJ. Suba responds. Am J Public Health 2007; 97(2):199-200.

49. Suba EJ, Murphy SK, Donnelly AD, Furia LM, Huynh MLD et al. Systems Analysis of Real-World Obstacles to Successful Cervical Cancer Prevention in Developing Countries. Am J Public Health 2006; 96:480–487.

50. WHO. Cervical Cancer Screening in Developing Countries. Report of a WHO Consultation. Geneva: World Health Organization, 2002.

51. Cervical Health Implementation Project (CHIP). Technical Report. University of Cape Town/ University of the Witwatersrand: EngenderHealth, 2004.

52. Lartey M, Joubert G, Cronjé HS. Knowledge, attitudes and practices of rural women in South Africa regarding the Pap smear. Int J Gynecol Obstet 2003; 83:315-316.

53. Leiman G. 'Project Screen Soweto' – A planned cervical cancer screening programme in a high-risk population. The S Afr Journal of Epidemiology and Infection 1987; 2:61-8.

54. Cronje HS, Trumpelmann MD, Divall PD, Scott LL, Middlecote BD, et al. Cervical cytological services in the Orange Free State. Demographic Characteristics. S Afr Med J 1989; 76:116.

55. Adam Y. Comments on cervical screening in Johannesburg Metro District. [E-mail] (Personal correspondence, 11 March 2008.)

56. Khanna N, Phillips MD. Adherence to care plan in women with abnormal Papanicolaou smears: A review of barriers and interventions. J Am Board Fam Pract 2001; 14:123–30.

57. Sibiya MN, Grainger L. An assessment of the implementation of the provincial cervical screening programme in selected Primary Health Care Clinics in the Ilembe Region, KwaZulu-Natal. Curationis 2007; 30(1):48-55.

58. Miller BA, Nazeer S, Fonn S, Brandup-Lukanow A, Rehman R, et al. Report on consensus conference on cervical cancer screening and management. Int J Cancer 2000; 86:440–7.

59. Alliance for Cervical Cancer Prevention (ACCP). Planning and implementing cervical cancer prevention and control programs: a manual for managers. Seattle: ACCP, 2004.

60. Gauteng Department of Health. Cervical screening statistics. District Health information system. Johannesburg, October 2009.

61. Johannesburg Regional Map. City of Johannesburg website. (Accessed 30 October 2009)
http://www.joburg.org.za/content/view/170/50/

62. Census 2001 Report. Statistics South Africa. Pretoria: Statistics South Africa, 2003. (Accessed 30 October 2009.)
http://www.statssa.gov.za/timeseriesdata/pxweb2006/Dialog/Saveshow.asp

63. Day C, Barron P, Monticelli F, Sello E, editors. The District Health Barometer 2007/08. Durban: Health Systems Trust, 2009.

64. Rakosa J, 2008. Correspondence on Health Facilities in the City of Johannesburg. [E-mail]. (Personal correspondence, 6 May 2008.)

65. Cardin VA, Grimes RM, Jiang ZD Pomeroy N, Harrell L et al. Low-income minority women at risk for cervical cancer: A process to improve adherence to follow-up recommendations. Public Health Reports 2001; 116: 608.

66. Lazcano-Ponce EC, Moss S, Alonso de Ruiz P, Salmeron Castro J, et al. Cervical cancer screening in developing countries: why is it ineffective? The case of Mexico. Arch Med Res. 1999; 30:240–250.

67. Stjernsward J, Eddy D, Luthra U, Stanley K. Plotting a new course for cervical cancer screening in developing countries. World Health Forum 1987; 8: 42–45.

68. Denny L. Cervical cancer: the South African perspective. FIGO 6th Annual Report on the Results of Treatment in Gynecological Cancer. Int J Gynaecol Obstet 2006; 95(S1): S211–214.

69. Hoque M, Hoque E, Kader SB. Evaluation of Cervical Cancer Screening Program at a Rural Community of South Africa. East African Journal of Public Health 2008; 5(2):111-116.

70. Chirenje ZM, Rusakaniko S, Kirumbi L, Ngwalle EW, Makuta-Tlebere P et al. Situation analysis for cervical cancer diagnosis and treatment in east, central and southern African countries. Bull World Health Organ 2001; 79(2):127-32.

71. Gakidou E, Nordhagen S, Obermeyer Z (2008) Coverage of cervical cancer screening in 57 countries: Low average levels and large inequalities. PLoS Med 5(6): e132. doi:10.1371/journal.pmed.0050132.

72. Budget Vote Speech 2001/2002 by Gauteng MEC for Health, Dr Gwen Ramokgopa. Johannesburg, 31 May 2001. (Accessed 30 October 2009) http://www.polity.org.za/polity/govdocs/speeches/2001/sp0531a.html

73. Jhala D, Eltoum I. Barriers to adoption of recent technology in cervical screening. CytoJournal 2007; 4:16.

74. Mock J, McPhee SJ, Nguyen T, Wong C, Doan H, et al. Effective Lay Health Worker Outreach and Media-Based Education for Promoting Cervical Cancer Screening Among Vietnamese American Women. Am J Public Health 2007; 9(97): 1693-1700.

75. Pillay P, Knight SE, Rmaih WNS. Cervical cancer screening in urban clinic in eThekwini municipal area. South Afr J Epidemiol Infect 2009; 24(2):18-20.

76. Miller AB. Quality assurance in screening strategies. Virus Res. 2002; 89:295-299.

77. Quinn M, Babb P, Jones J, Allen E. Effect of screening on incidence of and mortality from cancer of cervix in England: evaluation based on routinely collected statistics. BMJ 1999; 318:904-908.

78. Weller DP, Patnick J, McIntosh HM, Dietrich AJ. Uptake in cancer screening programmes. Lancet Oncol 2009; 10:693-99.

79. Risi L, Bindman JP, Campbell OMR, Imrie J, Everett K, et al. Media interventions to increase cervical screening uptake in South Africa: an evaluation study of effectiveness. Health Education Research 2004; 19(4):457–468.

80. Von Zuben MV, Derchain SF, Sarian LO, Westin MC, Thuler LCS et al. The impact of a community intervention to improve cervical cancer screening uptake in the Amazon region of Brazil. Sao Paulo Med J. 2007; 125(1):42-5.

81. Mauad EC, Nicolau SM, Moreira LF, Haikel Jr RL, Longatto-Filho A, et al. Adherence to cervical and breast cancer programs is crucial to improving screening performance. Rural and Remote Health 2009; 9:1241.

82. Bailie RS, Bourne D. Surveillance for Equity in Cervical Cytology Screening. Int J Epid. Year; 25(1):46-52.

83. Bahamon C, Dwyer J, Buxbaum A. Leading a change process to improve health service delivery. Bull World Health Organ 2006; 84:658-661.

84. Sasieni P, Adams J, Cuzick J. Benefit of cervical screening at different ages: evidence from the UK audit of screening histories. British Journal of Cancer 2003; 89: 88-93.

85. Sasieni P, Castanon A, Cuzick J. Effectiveness of cervical screening with age: population based case-control study of prospectively recorded data. BMJ 2009; 339:2968.

86. Sigurdsson K, Adalsteinsson S. Risk variables affecting high-grade Pap smears at second visit: effects of screening interval, year, age and low-grade smears. Int J Cancer 2991; 94:884–888.

87. Stout NK, Goldhaber-Fiebert JD, Ortendahl JD, Goldie SJ. Trade-offs in Cervical Cancer Prevention- Balancing Benefits and Risks. Arch Intern Med. 2008; 168(17):1881-1889.

88. Masilela M, 2009. Discussion on age at which to initiate cervical screening. 12th Annual Gauteng Department of Health Prakash Vallabh Primary Health Care Research Conference. [Public comment] (Personal communication, 1 Sep 2009).

89. Moodley JR, Constant D, Hoffman M, Salimo A, Allan B, et al. Human papillomavirus prevalence, viral load and pre-cancerous lesions of the cervix in women initiating highly active antiretroviral therapy in South Africa: a cross-sectional study. BMC Cancer 2009; 9:275.

90. Peckham S, Hann A. A sexual health prevention priority. Bull World Health Organ 2008; 86:490-491.

91. Bomela N, Stevens M. Cervical Cancer and HIV: The intimate connection Policy Brief #2. Durban: Health Systems Trust, 2009.

92. Centers for Disease Control: 1997 USPHS/IDSA Guidelines for the prevention of opportunistic infections in persons infected with human immunodeficiency virus. MMWR 1997; 46:1-26.

93. Michelow PM, Wright CA, Mayer NT, Leiman G. Evaluation of the interim cervical screening programme in the greater Johannesburg metropolitan area. S Afr J Epidemiol Infect 1999; 14:36-39.

94. Dickinson JA. Cervical screening: time to change the policy. MJA 2002; 176: 547-550.

95. Ruffin MT. Cervical Cancer Screening: Issues of Collecting Tools and Reporting. Arch Fam Med 1993; 2: 261-3.

96. Rylander E. Negative smears in women developing invasive cervical cancer. Acta Obstet Gynecol Scand. 1977; 56:115-118.

97. Kristensen GB, Skyggebjerg KD, Holund B, Holm K, Hansen MK. Analysis of cervical smears obtained within three years of the diagnosis of invasive cervical cancer. Acta Cytol. 1991; 35:47.

98. Gage JC, Ferreccio C, Gonzales M, Arroyo R, Huivin M, et al. Follow-up care of women with an abnormal cytology in a low-resource setting. Cancer Detect Prev 2003; 27:466-471.

99. Denny L, Kuhn L, Pollack A, Wright TC Jr. Direct visual inspection for cervical cancer screening. Cancer 2002; 94(16):1699-1707.

100. Forbes C, Jepson R, Martin-Hirsch P. Interventions targeted at women to encourage the uptake of cervical screening. Cochrane Database of Systematic Reviews 2007, Issue 4. Art. No.: CD002834. DOI: 10.1002/14651858.CD002834.

101. Agurto I, Bishop A, Sanchez G, Betancourt Z, Robles S. Perceived barriers and benefits to cervical cancer screening in Latin America. Prev Med 2004; 39:91-98.

102. Emdon S, Gerad U, Jones R. Knowledge about and utilisation of facilities for cervical smears among black women in Johannesburg. South African Medical Journal 1984; 65:289-290.

103. Korn AP, Autry M, DeRemer PA, Tan W (1994) Sensitivity of the Papanicolaou smear in human immunodeficiency virus-infected women. Obstet. Gynecol. 1994; 83: 401-404.

104. Goldhaber-Fiebert JD, Denny LA, De Souza M, Kuhn L, Goldie SJ. Program Spending to Increase Adherence: South African Cervical Cancer Screening. PLoS ONE 2009; 4(5): e5691. doi:10.1371/journal.pone.0005691.

105. Hermens RPMG, Hak E, Hulscher MEJL, Mulder J, Tacken MAJB et al. Improving population-based cervical screening in general practice: effects of a national strategy. International Journal for quality in healthcare 1999, 11(3):193-200.

106. Benatar SR. Health Care Reform and the Crisis of HIV and AIDS in South Africa. N Engl J Med, 351; 1:81-92.

107. Fonn S. Human resource requirements for introducing cervical screening – who do we need where? S Afr Med J 2003; 93(10):901-903.

108. Kitchener HC, Burnett RA, Wilson ESB, Cordiner JW. Colposcopy in a family planning clinic: A future model? BMJ 1987; 294:1313.

109. Tulinius H, Geirsson G, Sigurdsson K, Day NE. Screening for cervix cancer in Iceland. In: McBrien DCH, Slater TF, editors. Cancer of the uterine cervix: biochemical and clinical aspects. Orlando: Academic Press, 1984.

110. A methodology for estimating national and provincial populations: The approach of Statistics South Africa. Statistical Release P0302. Pretoria: Statistics South Africa, 2007.

111. Dorrington R, Bradshaw D, Bourne D. Two steps forward, one step back: Comment on adult mortality (age 15 - 64) based on death notification data in South Africa for 1997 – 2001. SAMJ, 2006; 96 (10):1031-1032.

112. Suba EJ, Viet/American Cervical Cancer Prevention Project. Crossing the quality chasm: a requirement for successful cervical cancer prevention in developing countries. Clin Lab Med. 2004; 24:945-963.

113. Pfaendler KS, Mwanahamuntu MH, Sahasrabuddhe VV, Mudenda V, Stringer JSA, et al. Management of cryotherapy-ineligible women in a “screen-and treat” cervical cancer prevention program targeting HIV-infected women in Zambia: Lessons from the field. Gynecol Oncol. 2008; 110(3):402-407.

114. Sherris JE, Wells E, Tsu V, Bishop A. Cervical Cancer in Developing Countries: A Situational Analysis. Washington, DC: The World Bank, 1993.

Appendix A: Data Collection Sheet

Facility Name:
Date:

No	Name	Date of Birth	Age	HIV status	Date Pap smear	Phone Number	Address	Result	Date informed	Referral hospital	Date Appointment	Attended Y/N
1												
2												
3												
4												
5												
6												
7												
8												
9												
10												
11												
12												

Appendix B: Ethics approval letter

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Jassat

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M080439**
PROJECT	An evaluation of the Cervical screening programme in the johannesbug Metro district gauteng Province
INVESTIGATORS	Dr W Jassat
DEPARTMENT	School of publich health
DATE CONSIDERED	08.04.25
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 08.05.07 **CHAIRPERSON** .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr M Kawonga

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES