

# Tackling Cervical Cancer: Improving Access to Cervical Cancer Services for Women in Southern Africa





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**October 2012**

## **SALC REPORT**

Tackling Cervical Cancer: Improving Access to Cervical Cancer Services for Women in Southern Africa  
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# Executive Summary

Cervical cancer is the leading cause of cancer death among women in southern Africa and is either the primary or the secondary cause of cancer death among women in all 10 countries in which the Southern Africa Litigation Centre (SALC) works. It is a disease of the female reproductive system, primarily caused by infection with the sexually transmitted human papillomavirus (HPV).

Cervical cancer is primarily an illness of inequality. About 86% of all cervical cancer cases occur in developing countries. Cancer of the cervix is the most common cancer among women in sub-Saharan Africa, which alone had 22% of all cervical cancer cases reported globally in 2010.

The disparity in cervical cancer incidence and mortality between high-income and low-income countries is due in part to the lack of services to prevent and treat cervical cancer in low-income countries. Based on the current medical science, cervical cancer is easily preventable and treatable. Deaths from cervical cancer in resource-rich countries are significantly lower, primarily due to prevention and early detection and treatment. However, access to cervical cancer screening services in southern Africa remains minimal.

The disproportionate cervical cancer burden in southern Africa is also due in part to the high prevalence of HIV in southern Africa. Many studies have shown a higher likelihood of pre-cursors to cervical cancer in women living with HIV.

Southern African countries have an obligation under international and regional law to provide effective cervical cancer services. The legal obligations emanating from these treaties require countries to issue and implement national policies on comprehensive cervical cancer management; ensure women have full information on cervical cancer; make available and provide access to prevention, screening and treatment services for cervical cancer; and make provision for palliative care for women with advanced cervical cancer.

This report is based on a combination of desktop research and field research in Namibia and Zambia. The desktop research was supplemented with focus group discussions, particularly with women living with HIV in Namibia and Zambia, to assess the availability of and access to cervical cancer services in both countries. A total of 181 women from both rural and urban areas, were interviewed in 15 focus group discussions.

## Research Findings

### **Policies**

Very few countries in southern Africa have comprehensive policies on cervical cancer. Neither Namibia nor Zambia has a comprehensive national policy on cervical cancer. To the extent that countries do have policies which address cervical cancer, the policies broadly mention the negative impact cervical cancer has on women, and provide only for screening services. Other critical aspects of cervical cancer management – including treatment for pre-cancerous lesions and cancer and palliative care – are often not addressed.

### **Awareness of cervical cancer**

There is a lack of awareness of cervical cancer throughout southern Africa. Awareness is higher in cities and among women living with HIV. There is a low level of awareness in rural areas and in some HIV-negative populations in Namibia and Zambia. In Namibia, concerns were raised regarding misinformation by healthcare workers to patients on the causes of cervical cancer.

### **Vaccines**

HPV vaccines are currently not widely available in the public sector in southern Africa, including in Namibia and Zambia. However, one or both of the HPV vaccines are licensed in most of the countries in the region and vaccines are generally available in the private sector.

### **Screening**

Screening services are primarily available in major cities. Screening services are either absent or infrequently available elsewhere. Different screening methods are used throughout southern Africa. Zambia primarily uses the visual inspection method. Namibia primarily uses Pap smear screening which creates obstacles to access, in part due to the lack of prioritisation of cervical cancer screening by healthcare workers.

### **Treatment**

Treatment of pre-cancerous lesions remains a challenge. In Zambia, treatment for pre-cancerous lesions is available in the capital city, but not widely available elsewhere. Similarly in Namibia treatment for pre-cancerous lesions is more widely and regularly available in the capital city. In addition, Namibia has not adopted the see-and-treat approach, thus requiring women to make multiple trips to access treatment services.

The treatment of invasive cervical cancer continues to be a major challenge in the region due to the lack of surgical facilities, skilled providers, chemotherapy and radiotherapy services. In Namibia and Zambia there is a dearth of treatment options, with hysterectomy being the most prevalent form of treatment. There are few treatment options available to women who want to preserve their fertility. Structural problems such as inadequate laboratory facilities and personnel shortages result in patients and health workers choosing treatment options without having proper diagnoses or adequate information.

## **Palliative care**

No country in southern Africa effectively provides for adequate pain relief. Neither Namibia nor Zambia has a comprehensive national palliative care policy. Where policies do address palliative care, they provide for home-based care but fail to address the administration of pain management.

## **Key Recommendations**

The failure to provide access to cervical cancer services results in the violation of fundamental rights and in the loss of countless lives. There is a serious and urgent need to improve services for cervical cancer in the southern Africa region. This report recommends that countries take the following steps to effectively address cervical cancer.

- Develop a comprehensive national policy on cervical cancer management. The policy must at minimum address the following:
  - primary prevention, including determining how awareness will be raised and information disseminated, and providing guidance on HPV vaccines;
  - secondary prevention or screening, including providing the age at which screening should start and the frequency of screening;
  - diagnosis;
  - treatment protocols for pre-cancerous lesions and invasive cervical cancer;
  - provision of palliative care; and
  - the needs of particularly vulnerable groups, such as women living with HIV.
- Widely disseminate information on cervical cancer, including risks, prevention options and treatment methods. Ensure information, both oral and in print is available in local languages.
- Provide free cervical cancer screening services throughout the country in the public health system.
- Integrate cervical cancer screening within existing sexual and reproductive health services.
- Explore avenues through which countries can acquire necessary medications, including the HPV vaccine and morphine, for wide use in the public health system.
- Allocate adequate human, financial and other resources to the management of cervical cancer.
- Establish effective cancer registries at regional and national levels to enable adequate assessment of the impact of cervical cancer screening programmes.
- Implement effective means of monitoring and evaluating cervical cancer programmes.

# Acronyms and Abbreviations

African Commission	African Commission on Human and Peoples' Rights
African Women's Protocol	Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa
AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral drugs
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CESCR	Committee on Economic, Social and Cultural Rights
CIDRZ	Centre for Infectious Disease Research in Zambia
CIN	Cervical intraepithelial neoplasia
GAVI	Global Alliance for Vaccines and Immunisation
HIV	Human immunodeficiency virus
HPV	Human papillomavirus
HRC	Human Rights Committee
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
LEEP	Electrosurgical excision procedure
LLETZ	Large loop excision of the transformation zone
NCD	Non-communicable diseases
SADC	Southern Africa Development Community
SIL	Squamous intraepithelial lesions
STI	Sexually transmitted infection
UDHR	Universal Declaration of Human Rights
UN	United Nations
UTH	University Teaching Hospital
VIA	Visual inspection with acetic acid
VILI	Visual inspection with Lugol's iodine
WHO	World Health Organization

# 1. Introduction

## 1.1 Background and purpose of this study

A woman dies every two minutes from cervical cancer.<sup>1</sup> Worldwide, cervical cancer afflicts more women than any other cancer apart from breast cancer.<sup>2</sup> In 2008, there were approximately 529,409 new cases of cervical cancer and 274,883 deaths from cervical cancer.<sup>3</sup>

Cervical cancer is primarily an illness of inequality. About 86% of all cervical cancer cases occur in developing countries.<sup>4</sup> Cancer of the cervix is the most common cancer among women in sub-Saharan Africa,<sup>5</sup> which alone had 22% of all cervical cancer cases reported globally in 2010.<sup>6</sup> In southern Africa, it is the primary or secondary cause of cancer death;<sup>7</sup> while it is the tenth most common cause of cancer death among women in high-income countries, such as the United States, Canada, Denmark, Norway, Sweden and Japan.<sup>8</sup> As of 2010, 66% of women diagnosed with cervical cancer in Africa each year were dying from the disease.<sup>9</sup>

The disparity in cervical cancer incidence and death between high-income and low-income countries is due in part to the lack of services to prevent and treat cervical cancer in low-income countries. Based on the current medical science, cervical cancer is preventable and

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<sup>1</sup>GAVI ALLIANCE, *Human papillomavirus vaccine support*, available at <http://www.gavialliance.org/support/nvs/human-papillomavirus-vaccine-support/>.

<sup>2</sup>WHO/ICO, HUMAN PAPILLOMAVIRUS AND RELATED CANCERS: AFRICA 5 (2010) [hereinafter WHO, HPV IN AFRICA 2010], available at <http://www.who.int/hpvcentre/en/>.

<sup>3</sup>*Id.*

<sup>4</sup>*Id.* at 5.

<sup>5</sup>Karly S. Louie et al., *Epidemiology and prevention of human papillomavirus and cervical cancer in sub-Saharan Africa: a comprehensive review*, 14 TROPICAL MED. & HEALTH J. 1287, (2009) [hereinafter Louie et al., *Epidemiology of HPV*].

<sup>6</sup>MOHAMMED H. FOROUZANFAR et al., INSTITUTE FOR HEALTH METRICS AND EVALUATION (IHME), THE CHALLENGE AHEAD: PROGRESS AND SETBACKS IN BREAST AND CERVICAL CANCER 18 [hereinafter IHME, CHALLENGE AHEAD], available at <http://www.healthmetricsandevaluation.org/publications/policy-report/challenge-ahead-progress-and-setbacks-breast-and-cervical-cancer>.

<sup>7</sup>WHO, HPV IN AFRICA 2010, *supra* note 2, at 13.

<sup>8</sup>Peter Maybarduk & Sarah Rimmington, *Compulsory Licenses: A Tool to Improve Global Access to the HPV Vaccine?* 35 AM. J.L. & MED. 324 (2009).

<sup>9</sup>WHO, HPV IN AFRICA 2010, *supra* note 2, at iv.

treatable.<sup>10</sup> Deaths from cervical cancer in resource-rich countries are significantly lower, primarily due to prevention, early detection and treatment.<sup>11</sup> However, access to cervical cancer screening services in southern Africa remains minimal. Consequently, a significant number of patients are diagnosed with advanced-stage disease, which carries a high morbidity and mortality rate.<sup>12</sup>

The disproportionate cervical cancer burden in southern Africa is also partly due to the high prevalence of HIV in southern Africa.<sup>13</sup> Many studies have shown a higher likelihood of pre-cursors to cervical cancer in women living with HIV.<sup>14</sup> Studies have also shown that treatment for pre-cancer is less effective in women living with HIV.<sup>15</sup> Southern Africa has the highest number of people living with HIV in the world.<sup>16</sup> Of those who are HIV positive, more than half are women. Furthermore, young women aged 15 to 24 are at least eight times more likely than men of the same age to be HIV-positive in sub-Saharan Africa.<sup>17</sup>

Cervical cancer can be prevented and treated by low-resource countries. In recent years, scientific, medical and public health advances have identified methods which can be used in low-resource settings to effectively address pre-cursors to cervical cancer. However, very few countries in southern Africa have utilised these tools.<sup>18</sup> Among 20 countries reporting cervical cancer screening activities in 2009 in sub-Saharan Africa as a whole, only 11 had ongoing country programmes. Of 49 projects initiated, only six were funded by the domestic government.<sup>19</sup>

<sup>10</sup>WHO, COMPREHENSIVE CERVICAL CANCER CONTROL: A GUIDE TO ESSENTIAL PRACTICE 3 (2006) [hereinafter WHO, CERVICAL CANCER GUIDE 2006], available at <http://www.who.int/reproductivehealth/publications/cancers/9241547006/en/index.html>.

<sup>11</sup>*Id.* at 16.

<sup>12</sup>Zvavahera M. Chirenje et al., *Situation analysis for cervical cancer diagnosis and treatment in East, Central and Southern African countries*, 79 BULLETIN WORLD HEALTH ORG. 127, 130 (2001) [hereinafter Chirenje et al., *Situation analysis for ECSA*].

<sup>13</sup>ALLIANCE FOR CERVICAL CANCER PREVENTION (ACCP), *Strategies for supporting women with cervical cancer*, 2 CERVICAL CANCER PREVENTION ISSUES IN DEPTH 1, 3 (2004), available at [http://www.path.org/publications/files/RH\\_supporting\\_women\\_iid.pdf](http://www.path.org/publications/files/RH_supporting_women_iid.pdf).

<sup>14</sup>Lesley Odendal, *Cervical cancer in women with HIV*, 174 HIV & AIDS TREATMENT IN PRACTICE 1, 6 (2011), available at <http://www.aidsmap.com/pdf/HATIP-174-February-17th-2011/page/1669154/>. **See also** Julius Atashili et al., *Potential Impact of Antiretroviral Therapy and Screening on Cervical Cancer Mortality in HIV-Positive Women in Sub-Saharan Africa: A Simulation*, 6 PLOS ONE e18527, e18527 (2011); M. Moodley et al., *Invasive cervical cancer and human immunodeficiency virus (HIV) infection: a South African perspective*, 11 INT'L J. GYNECOLOGICAL CANCER 194, 194 (2001).

<sup>15</sup>Odendal, *supra* note 14, at 9.

<sup>16</sup>UNAIDS, GLOBAL REPORT 28 (2010), available at [http://www.unaids.org/globalreport/documents/20101123\\_GlobalReport\\_full\\_en.pdf](http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf).

<sup>17</sup>UN WOMEN, *Gender Equality, Women and HIV*, available at [http://www.unwomen.org/wp-content/uploads/2011/06/HLMonAIDS\\_KeyDataStatsOnGenderEqualityWomenAndHIVaids\\_20110606.pdf](http://www.unwomen.org/wp-content/uploads/2011/06/HLMonAIDS_KeyDataStatsOnGenderEqualityWomenAndHIVaids_20110606.pdf).

<sup>18</sup>Rose I. Anorlu, *Cervical cancer: the sub-Saharan African perspective*, 16 REP. HEALTH MATTERS 41, 41 (2008). **See also** ACCP, *The case for investing in cervical cancer prevention*, 3 CERVICAL CANCER PREVENTION ISSUES IN DEPTH 1, 1 (2004), available at [http://screening.iarc.fr/doc/RH\\_accp\\_case.pdf](http://screening.iarc.fr/doc/RH_accp_case.pdf) [hereinafter ACCP, *The case for investing in cervical cancer prevention*].

<sup>19</sup>Louie et al., *Epidemiology of HPV*, *supra* note 5, at 1294.

Some of the primary reasons advanced for the higher cervical cancer incidence and mortality in southern Africa are the lack of awareness of cervical cancer among the population, healthcare providers and policy-makers;<sup>20</sup> non-existent service policies;<sup>21</sup> and a lack of political will in Africa to provide for the sexual and reproductive health needs of women, including for cervical cancer.<sup>22</sup>

Effectively addressing cervical cancer, and saving thousands of women from preventable death, is critical for southern African governments. In sub-Saharan Africa, cervical cancer afflicts women between 35-45 years of age, at a time when they are most productive and essential to the family unit.

Women's sexual and reproductive rights have often been overlooked or under-prioritised by governments, given the secondary status of women.<sup>23</sup> Globally, more than 13 million women are infected with both HIV and the virus causing cervical cancer, yet services for these women are extremely limited, both in terms of finances and the science available.<sup>24</sup>

This report seeks to address this priority gap through discussing the nature of cervical cancer and the services available to address pre-cursors to cervical cancer and to treat invasive cancer. The report will then discuss the state of cervical cancer services in southern Africa, particularly in Namibia and Zambia.<sup>25</sup> This research report is aimed at national and regional stakeholders, especially government officials and officials at human rights mechanisms throughout southern Africa.

## 1.2 Methodology

This study is based on a combination of desktop research and field research in Namibia and Zambia.

The legal and policy analysis included a review of relevant national policies such as cancer, sexual and reproductive health, HIV and gender policies; national laws and constitutions;

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<sup>20</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 16.

<sup>21</sup>Louie et al., *Epidemiology of HPV*, *supra* note 5, at 1287.

<sup>22</sup>*Id.*

<sup>23</sup>See, e.g., THE INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV/AIDS (ICW), THE FORCED AND COERCED STERILIZATION OF HIV POSITIVE WOMEN IN NAMIBIA [hereinafter ICW, STERILIZATION IN NAMIBIA], available at <http://www.icw.org/files/The%20forced%20and%20coerced%20sterilization%20of%20HIV%20positive%20women%20in%20Namibia%2009.pdf>.

<sup>24</sup>MIRANDA S. BALKIN, UNIFEM, CERVICAL CANCER PREVENTION AND TREATMENT: SCIENCE, PUBLIC HEALTH AND POLICY OVERVIEW 4 (2007) [hereinafter UNIFEM, BACKGROUND PAPER], available at [http://www.rho.org/files/UNIFEM\\_HPVC-Conference\\_BGpaper\\_1\\_2007.pdf](http://www.rho.org/files/UNIFEM_HPVC-Conference_BGpaper_1_2007.pdf).

<sup>25</sup>For the purposes of this research, southern Africa refers to the 10 countries in which the Southern Africa Litigation Centre (SALC) operates. These countries are Angola, Botswana, the Democratic Republic of Congo (DRC), Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia and Zimbabwe. It should also be noted that while these countries are often referred to as being in southern Africa, the World Health Organization (WHO), from which most statistical data in this report will be drawn, uses a different regional classification which places Angola and the DRC in Middle Africa; Malawi, Mozambique, Zambia and Zimbabwe in eastern Africa; and Botswana, Lesotho, Namibia and Swaziland in southern Africa. *See* WHO, HPV IN AFRICA 2010 *supra* note 2, at 3; *and* IHME, Challenge Ahead, *supra* note 6, at 27.

international and regional treaties; reports to relevant international and regional human rights treaty monitoring bodies; statements by treaty monitoring bodies; and other secondary sources such as books, journal articles and news articles.

To verify some of the initial desktop findings, 69 questionnaires were sent to a wide variety of civil society stakeholders working in health, sexual reproductive health, HIV and women's rights in southern Africa. A copy of the questionnaire can be found in Annexure one. We received 13 responses.

The desktop research was supplemented with focus group discussions, particularly with women living with HIV in Namibia and Zambia, to assess the availability of and access to cervical cancer services in both countries. These two countries were chosen based on the incidence and mortality rates of cervical cancer and HIV.<sup>26</sup>

A total of 181 women from both rural and urban areas were interviewed in 15 focus group discussions. In Namibia, seven focus group discussions with a total of 86 participants were conducted in Windhoek,<sup>27</sup> Okahandja,<sup>28</sup> and Otjiwarongo.<sup>29</sup> In Zambia, eight focus group discussions with a total of 95 participants were conducted in Lusaka<sup>30</sup> and Chipata.<sup>31</sup> Women interviewed included those living with and without HIV, and ranged in age from 16 to 66.<sup>32</sup>

### 1.3 Limitations of the study

All attempts were made to access the latest and most relevant national policies. However, this was not always possible. Our requests for current policies from government officials in Namibia and Zambia remained unanswered. We have thus used those policies which were available online.

Due to time constraints, it was not possible to conduct official interviews with healthcare providers. However, three professional nurses were part of some focus group discussions in Namibia. While some interesting insights were gleaned from their experiences, their views should not be seen as broadly representative of all healthcare workers.

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<sup>26</sup>Namibia has the lowest age standardised cervical cancer incidence and mortality rates in the region, while Zambia has the second highest age standardised cervical cancer incidence and mortality rates in Africa. **See** WHO, HPV IN AFRICA 2010 *supra* note 2, at 6 & 13. Cervical cancer is said to account for 30% or 1,650 of all cancer cases and 81% of patients die from the disease in Zambia. Brian Moonga, *Zambia strives to pin down cervical cancer*, 20 AORTIC NEWS (Afr. Org. Res. & Training in Cancer), Nov. 2011 at 5, available at [http://www.aortic-africa.org/images/uploads/Newsletter\\_2011\\_2nd\\_edition\\_-\\_Nov\\_2011\\_-\\_FINAL.pdf](http://www.aortic-africa.org/images/uploads/Newsletter_2011_2nd_edition_-_Nov_2011_-_FINAL.pdf).

<sup>27</sup>Windhoek is the capital city of Namibia. It is located in the Khomas region.

<sup>28</sup>Okahandja is a small town located in Otjozondjupa region.

<sup>29</sup>Otjiwarongo is the capital of Otjozondjupa region.

<sup>30</sup>Lusaka is the capital city of Zambia. It is located in Lusaka province.

<sup>31</sup>Chipata is the capital of the Eastern province.

<sup>32</sup>Informed consent was sought from all participants prior to commencing the discussions. All participants were provided with a small stipend to reimburse their transport costs.



In addition, translation during interviews, particularly in Namibia, was a challenge as specific terminology for sexual and reproductive health was difficult to translate into local languages.<sup>33</sup>

Participants in the field research were asked to fill out a demographics data form. Some of the numerical data gathered from the forms is included in the report. This data is intended solely to emphasise observations. No assertion that the quantitative data can be used for statistical extrapolations or generalisations is implied or intended.

The findings within this publication are designed to be illustrative. While every effort was made to provide accurate information based on the sources located, some findings may be outdated or may have been rendered outdated after publication of this report. SALC invites any such relevant information to be brought to its attention.

## 1.4 Structure of the report

This report is divided into five sections:

- Section one outlines the purpose of the research, the research methodology and limitations, as well as the structure of the report.
- Section two gives a brief overview of cervical cancer. It covers the causes of cervical cancer, and the prevention and treatment of the disease. It also explains the intersections between HIV and cervical cancer and the recommended management of cervical cancer in women living with HIV.
- Section three presents the research findings on cervical cancer-related policies and the availability of and access to cervical cancer services in southern African countries, particularly in Namibia and Zambia.
- Section four identifies the key legal obligations that arise under international and regional human rights treaties in relation to the provision of cervical cancer services, and assesses the compliance of national policies and services with these legal obligations.
- Section five offers recommendations to policy makers and other stakeholders in southern Africa on how to address cervical cancer effectively.

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<sup>33</sup>For example, translators found it very difficult to translate words such as cervix or lesions.



## 2. Background

This section discusses the risk factors, causes and development of cervical cancer. It also discusses prevention options; how to diagnose cervical cancer; treatment options; palliative care; and the link between HIV and cervical cancer. Although several international and national guidelines are referred to in this section, the most relevant to this discussion are the World Health Organization's (WHO) Comprehensive Cervical Cancer Control: a Guide to Essential Practice (WHO Guide to Essential Practice)<sup>34</sup> and the International Federation of Obstetrics and Gynaecology (FIGO)-authored Global Guidance for Cervical Cancer Prevention and Control (FIGO Cervical Cancer Guidance).<sup>35</sup> The WHO Guide to Essential Practice is currently undergoing a review to address changes in the scientific knowledge of cervical cancer and its management since its initial promulgation in 2006.<sup>36</sup> The FIGO Cervical Cancer Guidance, developed in 2009, reflects more recent scientific research and advancements, such as vaccinations and the impact of HIV on cervical cancer. Given that, this report relies more on the FIGO Cervical Cancer Guidance.

### 2.1 What is cervical cancer?

Cervical cancer is a disease that begins in the cervix of the female reproductive system.<sup>37</sup> The cervix is the lower portion of the uterus that connects the upper vagina to the uterus. The primary risk factor for developing cervical cancer is being infected with the human

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<sup>34</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10.

<sup>35</sup>INT'L FEDERATION OF GYNAECOLOGY & OBSTETRICS (FIGO), GLOBAL GUIDANCE FOR CERVICAL CANCER PREVENTION AND CONTROL (2009) [hereinafter FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009], available at <http://www.igo.org/news/igo-congress-news-igo-global-guidance-cervical-cancer-prevention-and-control-1>.

<sup>36</sup>The FIGO Cervical Cancer Guidelines anticipated a revised edition of the WHO Guide to Essential Practice in 2011 (see *id.* at 4). Dr K Mbaye of WHO/AFRO and Dr V Tsu of PATH suggested that a comprehensive revised document should be available by the end of 2012. *African Process in Cervical Cancer Prevention and the Road Forward*, CERVICAL CANCER ACTION (Mar. 20, 2012), available at <http://www.cervicalcanceraction.org/multimedia/webinar20march2012/lib/playback.html>.

<sup>37</sup>Cancer is a term used for "the malignant, autonomous and uncontrolled growth of cells and tissues. Such growth forms tumours, which may invade surrounding and distant parts of the body, destroying normal tissues and competing for nutrients and oxygen. Metastases occur when small groups of cells become detached from the original tumour, are carried to distant sites via the blood and lymph vessels, and start new tumours similar to the original one". WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 35.

papillomavirus (HPV), a common virus that is transmitted through sexual contact.<sup>38</sup> Cervical cancer is a slow-growing cancer and can take 10 to 20 years to develop fully. Due to this, preventive methods – such as vaccines, screening and treatment of pre-cancer – can be very effective. The stage of the disease greatly determines the treatment methods used.<sup>39</sup> Once the cervical cancer becomes invasive, there remain a number of treatment options – including chemotherapy, radiation therapy and hysterectomy – but their effectiveness is greatly reduced.

### **2.1.1 Risk factors and causes of cervical cancer**

Most cases of cervical cancer are caused by high-risk types of HPV.<sup>40</sup> HPV infection is very common worldwide.<sup>41</sup> Roughly 50-80% of all sexually active people will be infected with HPV during their lifetimes.<sup>42</sup> HPV is sexually transmitted, but penetrative sex is not required for transmission; skin-to-skin genital contact is a well-recognised mode of transmission.<sup>43</sup> There are many different types of HPV, at least 13 of which can cause cancer.<sup>44</sup> The most common cancer-causing types are 16 and 18, which are found in 70% of all cervical cancers reported.<sup>45</sup>

Factors that affect whether or not an HPV-infected woman develops cancer are numerous and include early sexual debut; smoking; having a high number of sexual partners and having partners who have multiple sexual partners; infection with HIV or other sexually transmitted infections; immunosuppression due to HIV or other diseases; multiple full-term pregnancies; and having first full-term pregnancy at an early age.<sup>46</sup>

### **2.1.2 Development of cervical cancer**

Though the primary cause of cervical cancer is infection by one or more of the high-risk types of HPV, most women infected with a high-risk type of HPV will not develop cancer.<sup>47</sup> Most HPV infections, regardless of type, are asymptomatic and resolve over a short period of time without treatment, as the woman's immune system will usually suppress or eliminate the HPV infection.<sup>48</sup>

<sup>38</sup>*Id.* at 16.

<sup>39</sup>For a discussion on the natural history of cervical cancer, causes, prevention and treatment, *see generally* WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at chapters 2-3. *See also* PATH, *Preventing cervical cancer: unprecedented opportunities for improving women's health*, 23 OUTLOOK, no. 1, June 2007, at 1, 3 [hereinafter PATH, *Preventing cervical cancer*], available at [http://www.rho.org/files/PATH\\_outlook23\\_1\\_web.pdf](http://www.rho.org/files/PATH_outlook23_1_web.pdf) *and* WHO, CERVICAL CANCER, HUMAN PAPILOMAVIRUS (HPV) AND HPV VACCINES: KEY POINTS FOR POLICY-MAKERS AND HEALTH PROFESSIONALS (2007), [hereinafter WHO, KEY POINTS FOR POLICY-MAKERS], available at [http://www.path.org/publications/files/RH\\_cxca\\_key\\_points\\_bklt.pdf](http://www.path.org/publications/files/RH_cxca_key_points_bklt.pdf).

<sup>40</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 35.

<sup>41</sup>WHO, KEY POINTS FOR POLICY-MAKERS, *supra* note 39, at 2.

<sup>42</sup>PATH, *Preventing cervical cancer*, *supra* note 39, at 2.

<sup>43</sup>WHO, KEY POINTS FOR POLICY-MAKERS, *supra* note 39, at 4.

<sup>44</sup>*Id.* at 2.

<sup>45</sup>*Id.* at 3.

<sup>46</sup>Karly S. Louie et al., *Early age at first sexual intercourse and early pregnancy are risk factors for cervical cancer in developing countries*, 100 BRIT. J. CANCER 1191, 1191-97 (2009); Helen Trottier & Eduardo L. Franco, *The epidemiology of genital human papillomavirus infection*, 24S1 VACCINE S14, pg. S1/11-S1/12 (2005); AM. CANCER SOC'Y, CERVICAL CANCER 5- 8 available at <http://www.cancer.org/acs/groups/cid/documents/webcontent/003094-pdf.pdf>.

<sup>47</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 35.

<sup>48</sup>*Id.*

In a small percentage of women, the HPV infection persists. Cancer of the cervix develops over time when persistent HPV infection triggers alterations in the cells of the cervix, called precursor lesions or cervical intraepithelial neoplasia (CIN), or more recently referred to as squamous intraepithelial lesions (SIL). These pre-cancerous changes, if left untreated, can lead to cancer. The lesions can progress from low grade (CIN 1) to high grade (CIN 2 and CIN 3) as their size, shape and number increase.<sup>49</sup>

Invasive cancer occurs when the abnormal cells invade the deep muscle, fibrous tissue and the organs surrounding the uterus. The process of finding out how far the cancer has spread is called staging. The stage of the cervical cancer tells us the size of the tumour, how deeply the tumour has invaded tissues within and around the cervix, and whether there is a spread to lymph nodes or distant organs. Determining the stage of the cancer is critical in determining what treatment should be offered.<sup>50</sup> Cervical cancer staging will be discussed in more detail under the treatment section below. Following its natural course, progression of the disease is slow and can take as long as 10 to 20 years from the initial infection with HPV to invasive cancer.

The time between initial HPV infection and development of cervical cancer generally occurs in the following stages:

Persistent HPV infection may lead to low grade cervical lesions, which are likely to resolve without treatment in the majority of cases. Low grade cervical lesions are defined by early changes in size, shape and number of abnormal cells formed on the surface of the cervix.



In a *minority* of women infected with HPV who developed low grade cervical lesions, these low grade lesions will progress to high grade cervical lesions or to pre-cancerous lesions involving cervical glandular cells. High grade cervical lesions are defined by a large number of pre-cancerous cells on the surface of the cervix that are distinct from normal cells.



If untreated, high grade cervical lesions have a *high* probability of becoming cancerous cells and invading deeper tissues of the cervix resulting in invasive cancer.<sup>51</sup>

## 2.2 Prevention

Prevention of cervical cancer can be achieved in two ways: preventing HPV infection – known as primary prevention – or detecting and treating pre-cursors to cervical cancer, known as secondary prevention.

### 2.2.1 Primary prevention

Primary prevention is a critical part of any successful cervical cancer strategy. Primary

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<sup>49</sup>Odendal, *supra* note 14, at 3.

<sup>50</sup>AM. CANCER SOC'Y, *supra* note 46, at 24.

<sup>51</sup>Odendal, *supra* note 14, at 3.

prevention of cervical cancer is about preventing HPV infection. This can be done in two ways: by managing risk factors through behaviour change or through vaccination with the HPV vaccine.

Prevention of cervical cancer rests significantly on whether communities are knowledgeable about the risk factors for cervical cancer and the availability of vaccines. The effectiveness of vaccines for HPV also relies on their availability within the public health system.

### **Managing risk factors through behaviour change**

One method of primary prevention that focuses on ensuring women protect themselves against HPV, recommends postponing sexual activity, decreasing the number of sexual partners and using barrier methods, such as condoms.<sup>52</sup>

For many reasons, primary prevention strategies have limited success: in part because women (and men) are not always in control of their sexual behaviour or their reproductive health decisions;<sup>53</sup> barrier methods do not fully protect against HPV as skin-to-skin genital contact without penetrative sex is a well recognised mode of transmission;<sup>54</sup> and none of these strategies, even if effectively employed, guarantees protection against HPV.

### **Vaccination**

Primary prevention can also be achieved through the use of vaccines. HPV vaccination is still in its infancy, with the first vaccine having been approved in June 2006. However, prevention of HPV infection through vaccination is the most effective primary prevention method available.<sup>55</sup>

Two HPV vaccines are currently available: Gardasil and Cervarix. Cervarix protects against two high-risk types of HPV: 16 and 18. Gardasil protects against four HPV types: HPV 6, 11, 16 and 18.<sup>56</sup> Trials have indicated that the two HPV vaccines are nearly 100% effective in protecting women from HPV types 16 and 18 which cause 70% of all cervical cancers.<sup>57</sup>

Both vaccines require three doses given over six months.<sup>58</sup> The vaccines have been proven to remain effective for at least five years, but may prove to be effective for longer as further research is conducted. In addition, research is under way to determine whether fewer doses provide adequate levels of protection.<sup>59</sup>

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<sup>52</sup>WHO, *CERVICAL CANCER GUIDE 2006*, *supra* note 10, at 46-47.

<sup>53</sup>Comm. on the Elimination of Discrimination against Women, General Recommendation No. 24: Women and Health (Article 12), para. 18, U.N. Doc. A/54/38 Rev. 1, [hereinafter CEDAW General Recommendation No. 24] available at [http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/77bae3190a903f8d80256785005599ff?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/77bae3190a903f8d80256785005599ff?Opendocument).

<sup>54</sup>Odenal, *supra* note 14, at 3; PATH, *Preventing cervical cancer*, *supra* note 39, at 2.

<sup>55</sup>PATH/RHO, *About Cervical Cancer*, available at <http://www.rho.org/about-cervical-cancer.htm>.

<sup>56</sup>CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC), *HPV Vaccine Information for Clinicians - Fact Sheet*, available at <http://www.cdc.gov/std/hpv/STDFact-HPV-vaccine-hcp.htm>.

<sup>57</sup>*Id.*

<sup>58</sup>FIGO, *GLOBAL GUIDANCE FOR CERVICAL CANCER 2009*, *supra* note 35, at 15.

<sup>59</sup>GAVI ALLIANCE, *supra* note 1.

Both Gardasil and Cervarix only work to prevent HPV infection. They will not treat an existing infection. That is why, to be most effective, the HPV vaccine should be given to women and girls prior to sexual activity.<sup>60</sup> The FIGO Cervical Cancer Guidance states that both vaccines are more effective in females younger than 15 years of age.<sup>61</sup> Current evidence supports HPV vaccination of young adolescent girls – from 9 to 13 years of age – prior to their sexual debut, to prevent cervical cancer in later life. Most medical guidelines, including the FIGO Cervical Cancer Guidance, recommend vaccination within this age bracket.<sup>62</sup>

HPV vaccination in older girls or women can prevent disease in women who have not been previously infected with the HPV types targeted by the vaccines. The FIGO Cervical Cancer Guidance, however, cautions that modelling studies suggest diminishing protection when the age of vaccination is increased.<sup>63</sup> While the vaccines are approved for women up to 26 years old, the American Cancer Society (ACS) recommends that vaccinations should primarily be given to women of 18 years or younger. The ACS found there was insufficient evidence to show that vaccination for women aged from 19 to 26 years would be beneficial. As a result, the ACS recommends that women between 19 and 26 years of age talk to their healthcare provider before making a decision about getting vaccinated.<sup>64</sup>

### **2.2.2 Secondary prevention**

Regardless of the possible efficacy of the vaccines, secondary prevention methods are critical in part, due to the lack of access to vaccines in southern Africa.<sup>65</sup> Secondary prevention of cervical cancer focuses on screening and early detection, followed by treatment of pre-cancerous lesions. There are several available methods of screening. They are the cytology-based method; visual inspection; and the HPV testing method. Each method is discussed below.

#### **Cytology-based screening (Pap smear screening)**

The cytology-based method has been the traditional method of preventing cervical cancer. The cytology-based method diagnoses cancer and pre-cancer by looking at cells under the microscope. The Papanicolau (Pap) smear or Pap test is a procedure used to collect cells from the cervix for cervical cytology testing.<sup>66</sup> A stiff brush or a small plastic spatula is used to scrape some cells off the surface of the cervix. These cells are mounted on a slide and examined by a pathologist for evidence of cancer or pre-cancerous changes.

The age and frequency of screening varies from country to country. The FIGO Cervical Cancer Guidance discusses current practice as follows:

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<sup>60</sup>AM. CANCER SOC'Y, *supra* note 46, at 16.

<sup>61</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 16.

<sup>62</sup>*Id.* at 19.

<sup>63</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 17.

<sup>64</sup>AM. CANCER SOC'Y, *supra* note 46, at 17.

<sup>65</sup>Joanna M. Cain et al., FIGO Working Group on Combating Cervical Cancer, *Control of cervical cancer: Women's options and rights*, 106 INT'L J. GYNECOLOGY & OBSTETRICS 141, 142 (2009) [hereinafter Cain, *Women's options*].

<sup>66</sup>AM. CANCER SOC'Y, *supra* note 46, at 11.

In developed countries, such as the United States, screening is initiated at age 21 or within three years of sexual activity and continues until the age of 65 or 70. In other countries, such as England, screening is initiated at age 25. It is performed every three years up to the age of 49, and then every five years until age 65 [...]. In low to middle resource countries, screening is inconsistent, maybe initiated in the mid 30s and then conducted every five years. If only one time screening is available, then it is usually performed between 35 and 40 years of age usually by visiting groups since no internal systems exist.<sup>67</sup>

In light of a lack of consensus, the FIGO Cervical Cancer Guidance recommends that:

- Initiation of cytological screening, where resources are available, should occur between ages 21 and 25. In low to medium resource areas, initiation should be at age 35.
- Interval of screening should follow accepted regional standards but should not be longer than five years in women under the age of 60.<sup>68</sup>

It also recommends that, as with other forms of screening, Pap smear screening should be provided to both vaccinated and unvaccinated women.<sup>69</sup>

The current WHO Guide to Essential Practice recommends that screening programmes in resource-limited settings start at 30 years and suggests that screening every three years is nearly as effective as yearly screening.<sup>70</sup> It also states that if resources are limited, screening every five to 10 years, or even just once between the age of 35 and 45 will significantly reduce cervical cancer mortality.<sup>71</sup>

Pap smear screening is technical, expensive and difficult to execute effectively in low-resource settings.<sup>72</sup> This is due to a number of factors. First, individuals need to be trained in how to properly obtain a viable sample for testing. Second, all samples need to be refrigerated during transportation from the clinic to the laboratory. Third, expensive infrastructure is needed in terms of facilities and equipment to read and preserve the slides, and reading the sample requires highly-skilled professionals. Finally, in the event of a positive test result, the patient returns for a second visit, and depending on institutional protocol, may need another Pap smear, further diagnosis or treatment.

### **Visual Inspection Methods**

Visual inspection methods are not as laboratory dependent and are better screening alternatives for developing countries. There are two methods of visual inspection: visual inspection with acetic acid (VIA) and visual inspection with Lugol's iodine (VILI). When the cervix is painted with iodine or a weak solution of acetic acid (white vinegar), the diseased areas appear to be a different colour than the rest of the cervix.

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<sup>67</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 45.

<sup>68</sup>*Id.*

<sup>69</sup>*Id.*

<sup>70</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 85.

<sup>71</sup>*Id.*

<sup>72</sup>UNIFEM, BACKGROUND PAPER, *supra* note 24, at 5.



Overall, visual inspection methods require considerably shorter training periods for healthcare workers than Pap smear screening.<sup>73</sup> In addition, costs related to programmes using the visual inspection method are significantly lower as the supply needs are minimal, requiring only acetic acid or iodine, a speculum, and a bright light.<sup>74</sup> Moreover, in most cases, this direct visualisation allows the clinician to offer treatment at the same visit by simply excising or freezing the diseased tissue, eliminating the need for return visits or multiple providers. Visual inspection screening methods thus offer a realistic option in a setting where women have little money, receive healthcare infrequently, and cannot be reliably contacted for follow-up.<sup>75</sup>

However, to be effective, programmes using visual inspection methods which are possibly subjective, should ensure that healthcare providers are well trained and that quality is regularly monitored and addressed when found lacking.<sup>76</sup>

For VIA-based screening, the FIGO Cervical Cancer Guidance recommends a three-to-five-year screening interval for women between the ages of 25-49 who have negative results. Given the link between HIV and cervical cancer, the FIGO Cervical Cancer Guidance recommends annual screening for HIV-positive women. The FIGO Cervical Cancer Guidance further recommends that women under 25 years of age should be screened only if they are at high risk for the disease, noting that women at high risk for cervical abnormalities are those who have had early sexual exposure, multiple partners, previous abnormal screening results, or are HIV-positive.<sup>77</sup> The FIGO Cervical Cancer Guidance cautions that VIA is not appropriate for women over 50 years of age, who it recommends should be screened at five year intervals using cytology or HPV DNA testing, discussed below.<sup>78</sup>

The WHO Guide to Essential Practice currently recommends the use of visual inspection methods in research and pilot sites only.<sup>79</sup> However, this is one of the recommendations under review.<sup>80</sup>

### **HPV testing**

There are two types of tests to detect high-risk types of HPV: HPV DNA and HPV RNA.<sup>81</sup> HPV DNA screening is highly recommended, but the current costs associated with this

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<sup>73</sup>UNIFEM, BACKGROUND PAPER, *supra* note 24, at 6; **see also** ACCP, *The case for investing in cervical cancer prevention*, *supra* note 18, at 15.

<sup>74</sup>UNIFEM, BACKGROUND PAPER, *supra* note 24, at 6.

<sup>75</sup>*Id.*

<sup>76</sup>Louie et al., *Epidemiology of HPV*, *supra* note 5, at 1294.

<sup>77</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 37.

<sup>78</sup>*Id.*

<sup>79</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 98.

<sup>80</sup>See *African Process in Cervical Cancer Prevention and the Road Forward*, *supra* note 36.

<sup>81</sup>There is however very little written on the RNA test. DNA is a nucleic acid containing the genetic instructions used in the development and functioning of all known living organisms. The DNA segments carrying this genetic information are called genes. RNA is one of the three major macromolecules (along with DNA and proteins) essential for all known forms of life. RNA is made up of a long chain of components called nucleotides. The sequence of nucleotides allows RNA to encode genetic information.

type of testing are significantly higher than for visual inspection methods.<sup>82</sup> In HPV DNA testing, HPV samples are collected in the same way as Pap smears: a cotton swab or a small brush is used to collect several samples of cells from the cervix. Cells are collected from the visible part of the cervix as well as from inside the opening of the cervix. The samples are then placed in collection tubes and sent to a laboratory for analysis.

Current innovation may make HPV DNA screening cost effective in low-resource settings. Rapid HPV DNA testing technology is emerging which requires only non-technical support and no electricity; this could overcome the cost and infrastructure needs of current HPV DNA testing.<sup>83</sup> It may also be possible for HPV DNA testing samples to be self collected,<sup>84</sup> which would reduce the need for medical personnel and permit women who are resistant to cervical examination by others to access screening services.<sup>85</sup>

HPV testing is not recommended for women below the age of 30 years. The FIGO Cervical Cancer Guidance recommends once or twice in a lifetime screening at age 35 and 45 years, with a confirmatory test for HPV-positive women being conducted either through VIA or Pap smear screening.<sup>86</sup> The WHO Guide to Essential Practice states that the use of HPV DNA tests as the primary screening method is recommended for use only in pilot projects or other closely monitored settings.<sup>87</sup> Replacing current screening approaches solely with the HPV DNA test has not yet been recommended by either FIGO or the WHO.

## 2.3 Diagnosis

If an abnormal result is obtained following a screening process, often additional tests will need to be done to determine the extent of the pre-cancer or cancer.

### 2.3.1 Colposcopy

Women who have an abnormal screening test generally undergo diagnostic testing, usually with colposcopy. Colposcopy involves examination of the vagina and cervix using a magnifying device with a powerful light source to identify any abnormal areas, highlighted through acetic acid or Lugol's iodine. If an abnormal area is seen on the cervix, a biopsy will be done. For a biopsy, a tissue sample is removed from the abnormal area and sent to a pathologist to determine whether the abnormal area is pre-cancerous, cancerous, or neither.<sup>88</sup>

Colposcopy must be performed by trained providers, and requires expensive, complex instruments. Furthermore, biopsy samples often need to be transported to a laboratory staffed by a pathologist, which is often impractical or impossible in low-resource countries.<sup>89</sup>

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<sup>82</sup>ACCP, *Recent Evidence on Cervical Cancer Screening in Low-Resource Settings* 7 (2011), available at [http://www.alliance-cxca.org/files/ACCP\\_cxca\\_screening\\_2011.pdf](http://www.alliance-cxca.org/files/ACCP_cxca_screening_2011.pdf) (last visited June 12, 2012).

<sup>83</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 50.

<sup>84</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 95.

<sup>85</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 49.

<sup>86</sup>*Id.* at 51.

<sup>87</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 96.

<sup>88</sup>*Id.* at 27. **See also** AM. CANCER SOC'Y, *supra* note 46, at 20.

<sup>89</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 129.

### 2.3.2 Single visit approach

In some low-resource settings, women are offered treatment for pre-cancerous lesions immediately, without undergoing further diagnostic testing. This is called the single visit, see-and-treat, or screen-and-treat approach.<sup>90</sup> In the single visit approach, the intent is to have screening and treatment performed at the same visit to minimise the chance of losing patients with abnormal results to follow-up. Although many combinations of testing and treatment are possible under a single visit approach, the most effective single visit approach at present is VIA, followed immediately by treatment through cryotherapy, which freezes off the abnormal area.<sup>91</sup>

## 2.4 Treatment

Numerous treatment options are available for pre-cancerous lesions and invasive cervical cancer.

### 2.4.1 Treatment of pre-cancer

The two primary treatment options for pre-cancerous cervical lesions are freezing off the abnormal area through cryotherapy or removal of tissue using loop electrosurgical excision procedure (LEEP), also called large loop excision of the transformation zone (LLETZ). Cold-knife conization can be used to remove lesions that cannot be treated using cryotherapy or LEEP/LLETZ. Hysterectomy is not recommended as treatment for pre-cancer.<sup>92</sup>

Cryotherapy is a safe and effective way of destroying cervical lesions on the ectocervix by freezing the relevant tissue. Guided by a timer or watch, the affected tissue is frozen for three minutes, allowed to thaw for five minutes and then refrozen for three minutes. As the FIGO Cervical Cancer Guidance states, “[c]ryotherapy is well suited for low resource settings. It requires no anaesthetic or electricity; the equipment is portable; the cost of consumables and equipment is less than electrosurgical methods; and with adequate training and supervision, primary healthcare professionals other than physicians are able to perform the technique”.<sup>93</sup>

LEEP/LLETZ involves using a thin wire in the shape of a loop to remove damaged tissue. The wire is attached to an electrical current, which turns the wire loop into a scalpel. For this procedure, a local anaesthetic is used, and the procedure can be done on an outpatient basis.<sup>94</sup> LEEP/LLETZ can be incorporated in a single visit approach.<sup>95</sup> LEEP/LLETZ procedures require trained medical practitioners and at least four weeks of on site training and retraining.<sup>96</sup>

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<sup>90</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 31.

<sup>91</sup>*Id.* at 32.

<sup>92</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 133.

<sup>93</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 57. **See also** *id.*, at 136; and WHO, USE OF CRYOTHERAPY FOR CERVICAL INTRAEPITHELIAL NEOPLASIA (2011), [hereinafter WHO, CRYOTHERAPY], available at [http://whqlibdoc.who.int/publications/2011/9789241502856\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789241502856_eng.pdf).

<sup>94</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 137. **See also** AM. CANCER SOC’Y, *supra* note 46, at 21.

<sup>95</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 62.

<sup>96</sup>*Id.* at 63.

Cold knife conization uses a surgical scalpel or a laser instead of a heated wire to remove tissue. General or local anaesthesia is required during the operation and the procedure is done in a hospital.<sup>97</sup>

### 2.4.2 Cancer treatment

If detected early, invasive cervical cancer can be treated successfully. The type of treatment needed and its effectiveness is determined by the stage of the cancer, which measures how far the cancer has advanced and assists in determining the most effective treatment. Hysterectomy and radiotherapy are the recommended primary treatments for cervical cancer. For advanced disease, radiotherapy is frequently used for palliation of symptoms. Chemotherapy may also be used with hysterectomy and radiotherapy.

A number of staging systems are used for cancer. The following is a summary of cervical cancer staging and treatment options.<sup>98</sup>

**Stage 0** is called carcinoma in situ, also referred to as high grade cervical lesions. It is diagnosed when abnormal cells are found in the innermost lining of the cervix. Stage 0 is not included in the FIGO system.

Treatment options for carcinoma in situ are the same as for other pre-cancers. Options include: cryotherapy; LEEP/LEETZ; and cold knife conization.<sup>99</sup> Pre-cancerous changes can recur and therefore patients who have undergone treatment must be closely monitored with regular follow-up.

**Stage I** is when the cancer is found only in the tissues of the cervix. In Stage I, standard treatment is a simple hysterectomy.<sup>100</sup> Cone biopsy may be used if preservation of fertility is necessary, in which case follow-up is critical to ensure that all the cancer has been removed by the cone biopsy. If the cancer has invaded the blood vessels or lymph vessels, a radical hysterectomy<sup>101</sup> along with removal of the pelvic lymph nodes will be necessary. To preserve fertility, a radical trachelectomy<sup>102</sup> can be done instead of the radical hysterectomy.

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<sup>97</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 138. **See also** AM. CANCER SOC'Y, *supra* note 46, at 21.

<sup>98</sup>*Id.* at 172-75. **See also** FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 69-70.

<sup>99</sup>Sometimes, hysterectomy is recommended. For those who wish to have children, treatment with a cone biopsy may be an alternative to hysterectomy in this case.

<sup>100</sup>Hysterectomy is surgery to remove the uterus (both the body of the uterus and the cervix) but not the structures next to the uterus. The vagina and pelvic lymph nodes are not removed. The ovaries and fallopian tubes are usually left in place unless there is some other reason to remove them. Any type of hysterectomy results in infertility (inability to have children).

<sup>101</sup>For this operation, the surgeon removes the uterus along with the tissues next to the uterus and the upper part of the vagina next to the cervix. The ovaries and fallopian tubes are not removed unless there is some other medical reason to do so.

<sup>102</sup>Radical trachelectomy, allows women to be treated for cancer while without losing their ability to have children. This procedure removes the cervix and the upper part of the vagina but not the body of the uterus. The surgeon places a "purse-string" stitch to act as an artificial opening of the cervix inside the uterine cavity. The nearby lymph nodes are also removed using laparoscopy which may require another incision (cut). The operation is done either through the vagina or the abdomen. After trachelectomy, some women are able to carry a pregnancy to term and deliver a healthy baby by caesarean section.

**Stage II:** In this stage, the cancer has spread beyond the cervix to the vagina, and in stage IIB to the tissues surrounding the uterus. Chemoradiation<sup>103</sup> or radical hysterectomy and bilateral pelvic lymphadenectomy<sup>104</sup> in selected patients with or without adjuvant radiotherapy<sup>105</sup> or chemoradiation are the recommended treatment options.

**Stage III:** In stage IIIA, the cancer has spread to the lower third of the vagina, but not to the pelvic wall. In stage IIIB, the cancer has spread to the pelvic wall and in some cases the tumor may be so large that it blocks the ureters, the tubes that connect the kidneys to the bladder. This can cause the kidneys to enlarge or stop working altogether. The cancer cells may at this stage also spread to the lymph nodes in the pelvis. Standard treatment at this stage includes chemoradiation or radiotherapy.<sup>106</sup>

**Stage IV:** During stage IVA, the cancer will have spread to the bladder or rectal wall and may also have spread to lymph nodes in the pelvis. In stage IVB, the cancer will have spread beyond the pelvis and pelvic lymph nodes to other places in the body, such as the abdomen, liver, intestinal tract, or lungs. Standard care at this stage is palliative radiotherapy<sup>107</sup> or chemotherapy.<sup>108</sup>

## 2.5 Palliative care

Palliative care addresses the needs of patients who are facing life-threatening illness and their families. It manages all aspects of the patient's wellbeing, including pain management and emotional and spiritual support. Palliative care focuses on increasing the patient's quality of life, not on treatment.<sup>109</sup>

The WHO defines palliative care as:

[A]n approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

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<sup>103</sup>This involves the use of chemotherapy to help radiation work well.

<sup>104</sup>This is an operation that involves the removal of the three groups of lymph nodes in the pelvis. These nodes are located close to the large blood vessels of the pelvis.

<sup>105</sup>Adjuvant therapy is treatment that is given in addition to the primary, main or initial treatment.

<sup>106</sup>Radiation therapy uses high energy x-rays to kill cancer cells. These x-rays may be given externally in a procedure that is much like having a diagnostic x-ray. This is called external beam radiation therapy. This treatment usually takes six to seven weeks to complete. For cervical cancer, this type of radiation therapy is often given along with low doses of chemotherapy with a drug called cisplatin.

<sup>107</sup>Palliative treatment means treatment to shrink a cancer, slow down its growth, or control symptoms. It does not aim to cure the cancer. Doctors use palliative radiotherapy to help shrink an advanced cancer or control symptoms of a cancer that has spread to give a better quality of life.

<sup>108</sup>Systemic chemotherapy uses anti-cancer drugs that are injected into a vein or given by mouth. These drugs enter the bloodstream and reach all areas of the body, making this treatment potentially useful for cancers that have spread to distant organs.

<sup>109</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 214.

## 2. BACKGROUND

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients' illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.<sup>110</sup>

The WHO Guide to Essential Practice recommends provision of palliative care services as part of management of advanced disease.<sup>111</sup> One key component of palliative care in cases of advanced cervical cancer is the management of the immense pain associated with late-stage disease.<sup>112</sup> Both the FIGO Cervical Cancer Guidance and the WHO Guide to Essential Practice recommend that opioid, non-opioid and adjuvant analgesics, particularly oral morphine, should be made available as part of comprehensive cervical cancer management programmes to address the pain experienced in progressive stages of the cancer.<sup>113</sup>

As access to cervical cancer screening is limited in southern Africa, a high number of patients are diagnosed with advanced-stage disease.<sup>114</sup> There is little treatment available in southern Africa for advanced cervical cancer.<sup>115</sup> Palliative care with symptom control and support thus becomes critical in the region.

### 2.6 Link between cervical cancer and HIV

Cervical cancer was recognised as an AIDS-defining illness and as a leading cause of mortality in HIV-positive women by the US Centers for Disease Control and Prevention (CDC) in 1993.<sup>116</sup> Although research into how specifically HIV affects the incidence of invasive cervical cancer is currently inconclusive and ongoing, there is no doubt that the negative effect of cervical cancer is exacerbated in southern Africa due in part to the high prevalence of HIV among women.

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<sup>110</sup>WHO, *Definition of Palliative Care*, available at <http://www.who.int/cancer/palliative/definition/en/>.

<sup>111</sup>WHO, *CERVICAL CANCER GUIDE 2006*, *supra* note 10, at 211.

<sup>112</sup>*Id.* at 214.

<sup>113</sup>*Id.* at 218; FIGO, *GLOBAL GUIDANCE FOR CERVICAL CANCER 2009*, *supra* note 35, at 71.

<sup>114</sup>Chirenje et al., *Situation analysis for ECSA*, *supra* note 12, at 130.

<sup>115</sup>*Id.*

<sup>116</sup>Centers for Diseases Control and Prevention, *1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults*, MMWR 41(RR-17), Dec. 18, 1992, available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/00018871.htm>.

Research studies have confirmed that women living with HIV are more susceptible to the pre-cursors to cervical cancer.<sup>117</sup> In addition, though not thoroughly researched, it is believed that the HPV vaccines are likely to be less effective for HIV-positive women.<sup>118</sup> Women living with HIV are almost five times more likely to be infected with HPV than HIV-negative women,<sup>119</sup> and are likely to develop persistent infection with multiple HPV types.<sup>120</sup> Low grade lesions have been found to occur at a younger average age in women living with HIV, and to progress more quickly if left untreated.<sup>121</sup> Compared with HIV-negative women, HIV-positive women with invasive cervical cancer are more likely to have advanced cervical cancer;<sup>122</sup> have persistent or recurrent disease at follow-up; have a shorter time to recurrence; have a shorter time for survival after diagnosis; and die of cervical cancer. Cervical cancer treatments also appear to be less effective in women living with HIV.<sup>123</sup>

In addition to women living with HIV being at greater risk of the pre-cursors to cervical cancer, they also are less likely to access existing cervical cancer services given the stigma and discrimination they often face in healthcare settings.<sup>124</sup>

### **2.6.1 Guidelines relating to cervical cancer management in women living with HIV**

In general, guidelines should not make distinctions between women living with HIV and HIV-negative women when providing for healthcare services, unless there is medical evidence to suggest that women living with HIV are differently affected by the particular illness. In the case of cervical cancer, there is clear medical evidence that women living with HIV are more susceptible to the pre-cursors to cervical cancer and thus, guidelines on cervical cancer services need to address the differential impact on women living with HIV.

#### **Screening**

While the WHO Guide to Essential Practice acknowledges that screening for cervical cancer in high HIV prevalence settings is particularly important because HIV-positive women have more persistent HPV infections and a higher incidence of pre-cancerous lesions, the WHO Guide to Essential Practice does not explicitly recommend more frequent screenings in high HIV prevalence settings or in women living with HIV.<sup>125</sup>

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<sup>117</sup>Fiona Hale, *Fact Sheet: HPV, Cervical Cancer and HIV: Screening and Prevention* (2009) [hereinafter Hale, *Fact Sheet*], available at <http://www.athenanetwork.org/assets/files/HIV%20&%20HPV%20Fact%20Sheet.pdf>.

<sup>118</sup>Hale, *Fact Sheet*, *supra* note 117.

<sup>119</sup>*Id.*

<sup>120</sup>Z.M. Chirenje, *HIV and cancer of the cervix*, 19 *BEST PRACTICE & RES. CLINICAL OBSTETRICS & GYNAECOLOGY* 269, 270 (2005) [hereinafter Chirenje, *HIV and cancer of the cervix*].

<sup>121</sup>Donna Rochon, *The human papillomavirus (HPV): lost in space*, *THE BODY PRO* (Winter 2007/2008), available at <http://www.thebodypro.com/content/art48893.html>.

<sup>122</sup>Chirenje, *HIV and cancer of the cervix*, *supra* note 120, at 272.

<sup>123</sup>*Id.*

<sup>124</sup>ICW, *STERILIZATION IN NAMIBIA*, *supra* note 23, at 4. **See generally** KAREN STEFISZYN et al., CENTRE FOR HUMAN RIGHTS, UNIVERSITY OF PRETORIA, *REALISING THE RIGHT TO HEALTH IN THE UNIVERSAL DECLARATION OF HUMAN RIGHTS AFTER 60 YEARS: ADDRESSING THE REPRODUCTIVE HEALTH RIGHTS OF WOMEN LIVING WITH HIV IN SOUTHERN AFRICA* (2009), available at [http://www.chr.up.ac.za/images/files/research/gender/publications/gender\\_realising\\_right\\_to\\_health\\_hiv\\_southern\\_africa.pdf](http://www.chr.up.ac.za/images/files/research/gender/publications/gender_realising_right_to_health_hiv_southern_africa.pdf).

<sup>125</sup>WHO, *CERVICAL CANCER GUIDE 2006*, *supra* note 10, at 86-87 (“Women should be offered the same cervical cancer screening options irrespective of their HIV status”).

However in 2008, the WHO issued guidelines on women living with HIV which acknowledged the emerging data on the interlinkages of HIV and cervical cancer and highlighted the urgent need to integrate effective cervical cancer screening with HIV care.<sup>126</sup> These guidelines recommend that, “[w]here available, women with HIV should be screened for cervical cancer initially and at regular (e.g. annual) intervals. If cervical screening tests are not available, persons should be referred to a higher-level of health care”.<sup>127</sup>

The FIGO Cervical Cancer Guidance provides specific guidelines for women living with HIV, recognising that women living with HIV are at high risk for cervical abnormalities. The FIGO Cervical Cancer Guidance recommends that HIV-positive women under 25 years of age should be screened using VIA methods and should be screened annually.<sup>128</sup> It also notes that women who have had early sexual exposure are at high risk for cervical cancer and recommends they start screening earlier if necessary.<sup>129</sup>

### **Vaccination**

The international guidelines recognise the dearth of information on the efficacy of the HPV vaccine for women living with HIV. The amount of protection conferred when an individual with a compromised immune system is vaccinated is not known.<sup>130</sup> Guidelines however, emphasise that “as the HPV vaccine is not a live virus, the vaccine is safe for HIV-positive individuals”.<sup>131</sup> The FIGO Cervical Cancer Guidance also highlights that the one research study available shows the “efficacy of HPV vaccines may be lower – but not insignificant – in HIV-positive individuals”.<sup>132</sup> Since HIV-positive women are known to be especially vulnerable to cervical cancer, the WHO suggests that the benefit of the HPV vaccine to this group remains high.<sup>133</sup>

### **Treatment**

The WHO Guide to Essential Practice provides that HIV-positive women should receive the same treatment options as HIV-negative women.<sup>134</sup> However, the WHO notes that “HIV-positive women are known to have higher rates of persistence, progression and recurrence of disease after treatment” and should therefore be monitored every six months after treatment, and promptly re-treated if high-grade lesions recur.<sup>135</sup>

The WHO recommends cryotherapy over no treatment in all women, including in women living with HIV, but in settings where LEEP/LLETZ is available and accessible, the WHO

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<sup>126</sup>WHO, ESSENTIAL PREVENTION AND CARE INTERVENTIONS FOR ADULTS AND ADOLESCENTS LIVING WITH HIV IN RESOURCE LIMITED SETTINGS (Jim Boothroyd, ed., 2008), available at [http://www.who.int/hiv/pub/prev\\_care/OMS\\_EPP\\_AFF\\_en.pdf](http://www.who.int/hiv/pub/prev_care/OMS_EPP_AFF_en.pdf).

<sup>127</sup>*Id.* at para. 4.6.4.

<sup>128</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 37.

<sup>129</sup>*Id.*

<sup>130</sup>*Id.* at 18.

<sup>131</sup>*Id.* at 27.

<sup>132</sup>*Id.*

<sup>133</sup>WHO, *HPV vaccines position paper*, *supra* note 62, at 129.

<sup>134</sup>WHO, CERVICAL CANCER GUIDE 2006, *supra* note 10, at 87.

<sup>135</sup>*Id.* at 134.



recommends treatment with LEEP/LLETZ over cryotherapy regardless of a women's HIV status.<sup>136</sup> The FIGO Cervical Cancer Guidance is less conclusive with respect to cryotherapy, providing that the effectiveness of cryotherapy in women with HIV should be further explored.<sup>137</sup> FIGO also generally cautioned that “women [living with HIV] may transmit the virus more readily after cryotherapy, and, therefore, require counselling regarding abstinence and condom use”.<sup>138</sup>

With respect to cold-knife conization, the FIGO Cervical Cancer Guidance confirms that cervical conization is safe and effective in women living with HIV and that the see-and-treat approach is feasible in low-resource settings for women living with HIV.<sup>139</sup>

## 2.7 Conclusion

Cervical cancer is both preventable and treatable if diagnosed early. Vaccinating against high-risk types of HPV, which cause most cases of cervical cancer, and regular screenings to address pre-cancerous cell changes are necessary to prevent cervical cancer. Early detection of invasive cancer is critical to effective treatment, and in those cases where the cancer is advanced and incurable, palliative care is essential for managing the patient's physical and mental pain. For women living with HIV, who are at greater risk for the pre-cursors to cervical cancer, specific guidelines should be issued to address their greater vulnerability.

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<sup>136</sup>WHO, CRYOTHERAPY, *supra* note 93, at 5.

<sup>137</sup>FIGO, GLOBAL GUIDANCE FOR CERVICAL CANCER 2009, *supra* note 35, at 59.

<sup>138</sup>*Id.* at 38.

<sup>139</sup>*Id.* at 65.



### 3. Research Findings:

## National Cervical Cancer Policies and Availability of and Access to Services

This section presents our findings based on interviews with women in Namibia and Zambia and a desktop review of cervical cancer policies and the availability of and access to cervical cancer services in southern Africa. In particular, this section covers the following key issues:

- National cervical cancer-related policies and guidelines;
- Availability of and access to prevention services;
- Availability of and access to treatment of pre-cancerous lesions and invasive cervical cancer; and
- Availability of and access to palliative care services.

While examples may be cited from other southern African countries, this section focuses on findings from Namibia and Zambia, where in-depth policy analysis and field research were done.

A total of 86 women participated in the research in Namibia through seven focus group discussions: three in Windhoek; two in Okahandja, and two in Otjiwarongo. The participants in Windhoek were primarily from Katutura township.<sup>140</sup> The Okahandja focus group participants were predominantly from Oshetu township. Participants in the Otjiwarongo groups were primarily from Orwetoveni and Tsaraxa-eibe townships. The majority of the Windhoek-based participants and participants in Otjiwarongo were women living with HIV. In Okahandja, only one woman reported herself to be HIV positive. One group in Windhoek was composed of young women aged 16-24, a few of whom were born with HIV.

In Zambia, 95 women participated in the research through eight focus group discussions: five in the greater Lusaka area and three in Chipata in the Eastern Province. In Lusaka, the research was conducted with women living in Kanyama, Matero, Kamwala, Kabangwe and Kalingalinga townships. In Chipata, participants were from several townships in and around Chipata. The majority of the research participants in Zambia (87%) were women living with HIV.

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<sup>140</sup>Katutura is the only township in Windhoek.

In both countries, most of the participants were either unemployed or employed in low-income, unskilled work. The majority of the women had attained low levels of formal education. For a detailed description of the demographics of the interviewees and the research schedule, see Annexure two.

### 3.1 Cervical cancer-related policies and guidelines

Issuing and implementing comprehensive national policies on all aspects of cervical cancer management are critical to effectively addressing cervical cancer in southern Africa.<sup>141</sup> A meeting held in 1998 to discuss the prevention and control of cervical cancer in the east and southern Africa region found that the absence of formal national policies and guidelines on cervical cancer was a key concern.<sup>142</sup> Our desktop review for cervical cancer policies in the region revealed that despite resolutions on adopting national policies and guidelines related to cervical cancer,<sup>143</sup> more than a decade on, there is still a dearth of clear and comprehensive national cervical cancer management guidelines and policies in the region.

The term “cervical cancer policies” in this report refers to the existence of formal governmental operational regulations, guidelines, norms, and standards related to cervical cancer.

Cervical cancer policies signal governments’ commitment to addressing cervical cancer, identify the steps that need to be taken, and indicate the funding and resources needed to address cervical cancer.<sup>144</sup>

In addition to the existence of a cervical cancer policy signalling political concern and commitment, policies also play an important role in raising awareness and providing information to the target population on the availability of services. Where there are no policies, or where these are not widely disseminated to stakeholders, women are not aware of the services that are available to them. As one participant in Namibia stated:

With HIV, we all know that when you test positive, they must do a viral load test and CD4 count test. We know that when you are below CD4 count 200, they must initiate you on treatment. Everybody knows the policy. We have [Information, Education and Communication] material in our support groups. But with this cervix cancer thing, we don’t know what we are entitled to.<sup>145</sup>

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<sup>141</sup>Atara Ntekim, *Cervical Cancer in Sub Sahara Africa*, in TOPICS ON CERVICAL CANCER WITH AN ADVOCACY FOR PREVENTION 59 (R. Rajamanickam ed., 2012), [hereinafter Ntekim, *Cervical Cancer in SSA*], available at [http://cdn.intechopen.com/pdfs/30747/InTech-Cervical\\_cancer\\_in\\_sub\\_sahara\\_africa.pdf](http://cdn.intechopen.com/pdfs/30747/InTech-Cervical_cancer_in_sub_sahara_africa.pdf).

<sup>142</sup>MEETING REPORT: PREVENTION AND CONTROL OF CERVICAL CANCER IN THE EAST AND SOUTHERN AFRICA REGION 5 (Stella Abwao et al., eds. 1998), at 42, available at [http://pdf.usaid.gov/pdf\\_docs/PNACK833.pdf](http://pdf.usaid.gov/pdf_docs/PNACK833.pdf).

<sup>143</sup>Resolutions were adopted at the 1997 Regional Health Ministers Conference in Mozambique, (a gathering of members of the Commonwealth Regional Health Community of East, Central, and Southern Africa (ECSA) and the 1998 meeting in Kenya. See *id.* at 2.

<sup>144</sup>WHO, NATIONAL CANCER CONTROL PROGRAMMES: POLICIES AND MANAGERIAL GUIDELINES 127-29 (2d ed., 2002), available at <http://whqlibdoc.who.int/hq/2002/9241545577.pdf>.

<sup>145</sup>Quote from Participant, Windhoek 3 Focus Group Discussion, in Windhoek, Namib. (Feb. 3, 2012).

Another noted:

You see, it's like you are being too forward. Even when you question the nurses about HIV, they don't like it. But at least that is common information, everyone knows it. Now if you [have a] question about a Pap smear, she really think[s] you are being forward. She will ask you who told you it's a must for you to have one.<sup>146</sup>

Neither Namibia nor Zambia has comprehensive guidelines on the management of cervical cancer. Where some guidance is available it tends to be inadequate, focusing on screening services with very limited guidance on other forms of prevention or treatment.

To effectively address cervical cancer, countries must issue a comprehensive cervical cancer policy. Such a policy should, at the minimum, address the following:

- primary prevention, including dissemination of information and education, and guidance on HPV vaccines;
- secondary prevention or screening, including providing the age at which screening should start and the frequency of screening;
- diagnosis;
- treatment protocols for pre-cancerous lesions and invasive cervical cancer;
- provision of palliative care; and
- the needs of particularly vulnerable groups, such as women living with HIV.

### **Policies and guidelines in Namibia**

There is no comprehensive policy in Namibia which provides guidance on vaccination or treatment options for cervical cancer. Existing policies note the impact of cervical cancer and provide guidelines for screening. The Namibia National Health Policy Framework (2010 - 2020) acknowledges that cancer is a growing public health problem.<sup>147</sup> The Family Planning Policy<sup>148</sup> and the National Policy on Reproductive Health<sup>149</sup> provide for the delivery of Pap smear screenings during family planning, post-natal, and outpatient visits. Namibia has specific guidelines on Pap smear screening.<sup>150</sup>

Similarly, with respect to women living with HIV, the National Guidelines for Antiretroviral Therapy (2010) recognises that HIV-infected women are at higher risk of infection with HPV and recommends annual Pap smear screening for all women with HIV, but fails to provide guidelines on other aspects of cervical cancer management, including treatment for pre-cancer and invasive cancer.<sup>151</sup>

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<sup>146</sup>Quote from Participant, Windhoek 3 Focus Group Discussion, in Windhoek, Namib. (Feb. 3, 2012).

<sup>147</sup>Rep. of Namib., Ministry of Health & Soc. Serv., *National Health Policy Framework* at 4.8 (2010-2020).

<sup>148</sup>Rep. of Namib., Ministry of Health & Soc. Serv., *Family Planning Policy* at 18 (1995).

<sup>149</sup>Rep. of Namib., Ministry of Health & Soc. Serv., *National Policy for Reproductive Health* at 4.2 (2001).

<sup>150</sup>Rep. of Namib., Ministry of Health & Soc. Serv., *Guidelines on Pap Smear Screening* (2010). We were unable to locate a copy of these guidelines, although partners in Namibia and our internet search confirm the existence of the document.

<sup>151</sup>Rep. of Namib., Ministry of Health & Soc. Serv. Directorate of Special Programmes, *National Guidelines for Antiretroviral Therapy* at 1.11.1 (2010).

### **Policies and guidelines in Zambia**

Zambia does not have comprehensive guidelines on the management of cervical cancer.<sup>152</sup> Several policy documents in Zambia mention cervical cancer.<sup>153</sup> However, important aspects such as target age and frequency of screening; treatment options and protocols for pre-cancerous lesions and invasive cervical cancer; and provision of palliative care are not provided for in policy or guidelines.

Many policies provide broad objectives to address cervical cancer, but fail to offer detailed guidance on how the objectives will be reached. The 2011-2015 Sixth National Development Plan (SNDP), aimed at priority setting and resource allocation for development, lists scaling up of treatment for cancers as a strategy for the HIV and AIDS sector, but provides no clear indication on how such a scale-up will be accomplished.<sup>154</sup>

The 2011-2015 National Health Strategic Plan (NHSP) also lists scaling up and expanding the coverage for reproductive health services including cervical cancer as a key strategy.<sup>155</sup> In addition, the NHSP affirms the findings of a needs assessment for the non-communicable diseases (NCDs) programme done in 2009, which identified inadequate drugs and lab reagents; inadequate diagnostic facilities; inadequate expertise; and lack of community awareness as key obstacles to the effective management of cervical cancer.<sup>156</sup> However, the NHSP does not fully address how to overcome these obstacles.

The budget accompanying the 2011 Ministry of Health Action Plan makes an allocation for “strengthened programmes for screening and treatment of cervical cancer” and for “the implementation of feasibility for HPV vaccine in Lusaka,” but fails to provide details on how programmes will be supported under the allocation.

Finally, the National Reproductive Health Policy,<sup>157</sup> which acknowledges that cervical cancer is a major cause of female mortality, provides for measures to create suitable conditions for screening, early diagnosis and treatment of all cancers of the reproductive system, including cervical cancer.<sup>158</sup> However, how these measures will be implemented and resourced remains unclear.

The piecemeal approach to addressing cervical cancer in national policies results in inconsistent commitment. For example, while the NHSP mentions cervical cancer, the Ministry of Health Action Plan for 2011, which provides the implementation roadmap for the priorities identified in the NHSP, fails to discuss cervical cancer in its section on

<sup>152</sup>Sharon Katai Kapambwe, REVIEW OF CERVICAL CANCER SCREENING IN ZAMBIA 7-8 (2008), 44th International Course in Health Development, Sept. 24, 2007-Sept. 12, 2008, Vrije University, Amsterdam [hereinafter Kapambwe, SCREENING IN ZAMBIA], available at <http://www.search4dev.nl/document/193921>.

<sup>153</sup>See, e.g., Rep. of Zam., Ministry of Health, *National Health Strategic Plan 2006 – 2010* at 7.2.3(6); Rep. of Zam., Sixth National Development Plan 2011-2015 at 3.3.1; and Rep. of Zam., Ministry of Health, *National Reproductive Health Policy* (2005).

<sup>154</sup>Rep. of Zam., *Sixth National Development Plan 2011-2015* at 3.3.1.

<sup>155</sup>Rep. of Zam., Ministry of Health, *National Health Strategic Plan (2011-2015)* at 5.1.2.4.2(1)(iii).

<sup>156</sup>*Id.* at Table 4.

<sup>157</sup>Rep. of Zam., Ministry of Health, *National Reproductive Health Policy* (2005).

<sup>158</sup>*Id.* at 4.10.2.

HIV and related diseases.<sup>159</sup> Without adequate follow-up through policies and regulations, cervical cancer management will continue to be ineffective. Similarly, many Zambian HIV policies address cervical cancer for women living with HIV, but the policies are not comprehensive, focusing primarily on screening. The Antiretroviral Therapy for Chronic HIV Infection in Adults and Adolescents New ART Protocols, issued by the Ministry of Health, provide specifically for an initial Pap smear screening, another screening after six months and if normal, then annually thereafter.<sup>160</sup> The Protocols provide that if Pap smear screening is unavailable, then VIA screening should be offered.<sup>161</sup>

The HIV guidelines, which do discuss cervical cancer, are silent on important issues apart from screening, such as testing for HPV and management of pre-cancerous lesions and advanced disease in women living with HIV. For example the National Guidelines on Management and Care for People Living with HIV and AIDS provide for testing of STIs in all individuals who seek an HIV test.<sup>162</sup> However, HPV is not identified as one of the STIs for which to test under the guidelines.<sup>163</sup>

### **Policies and guidelines in southern Africa**

Very few countries in southern Africa have comprehensive policies on cervical cancer. Cervical cancer is mentioned broadly in national health strategic plans, reproductive health policies, gender policies and HIV policies, but details regarding all aspects of cervical cancer management are not addressed. For example, in Malawi, the National Plan of Action for the National Gender Programme had as one of its goals, “to facilitate the development and maintenance of gender sensitive database PAC, EC, cervical cancer, PMTCT and youth friendly health service delivery”.<sup>164</sup> The National Health Policy of Swaziland notes cervical cancer as accounting for 43.1% of all cancer among women, but provides no additional detail.<sup>165</sup>

Some countries, such as Malawi and Lesotho, are reported to have screening guidelines.<sup>166</sup> It is not clear whether other aspects of cervical cancer management, including treatment for pre-cancer and cancer and palliative care are covered in these countries.

At least one country in southern Africa does have a comprehensive cervical cancer policy. The Botswana Policy Guideline and Service Standards: Sexual and Reproductive Health (Botswana Policy), issued by the Ministry of Health to facilitate access to sexual and

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<sup>159</sup>Rep. of Zam., Ministry of Health, *2011 Action Plan* at 9-10[hereinafter Zam. MOH, *2011 Action Plan*].

<sup>160</sup>Rep. of Zam., Ministry of Health, *The Antiretroviral Therapy for Chronic HIV Infection in Adults and Adolescents New ART Protocols* at 17 (2007).

<sup>161</sup>*Id.*

<sup>162</sup>Rep. of Zam. & Nat’l AIDS Council, *The National Guidelines on Management and Care for People Living with HIV and AIDS* at 9 (2008) [hereinafter Government of Zam., *National Guidelines for PLWHA*].

<sup>163</sup>*Id.* at 12-15.

<sup>164</sup>Gov’t of Malawi, *National Plan of Action for the National Gender Programme* (2005-2008), Objective 3.1.5.

<sup>165</sup>Kingdom of Swaz., Ministry of Health & Soc. Welfare, *Swaziland National Health Policy* at 8.

<sup>166</sup>PATH, IMPROVED CERVICAL CANCER PREVENTION: PLANNING NOW FOR A BETTER FUTURE 30, 34 (2010) [hereinafter PATH, IMPROVED PREVENTION], available at [http://www.rho.org/files/PATH\\_Africa\\_cxca\\_conf\\_report\\_2010.pdf](http://www.rho.org/files/PATH_Africa_cxca_conf_report_2010.pdf).

reproductive health services, highlights the cervical cancer services provided for primary prevention, secondary prevention, early diagnosis, and treatment and palliative care.<sup>167</sup> It provides for secondary screening for individuals from 20-65 years of age at three- to five-year screening intervals.<sup>168</sup>

The impact of a comprehensive policy addressing cervical cancer is clear. The Botswana Policy has successfully raised public awareness, resulting in more women accessing Pap smear screening, from 5,000 screenings per year before 2002 to 32,000 per year in 2009.<sup>169</sup>

Very few countries in southern Africa have comprehensive cervical cancer policies. Among the countries that do have policies that address cervical cancer, the policies focus primarily on screening, but fail to address other aspects of cervical cancer management.

## 3.2 Availability of and access to prevention services

Prevention services are critical in addressing cervical cancer at early stages. Prevention services include:

- information on cervical cancer, its causes and prevention methods;
- vaccination against HPV; and
- screening services, followed up with treatment of pre-cancerous lesions where necessary.

### 3.2.1 Availability of and access to information on cervical cancer

Primary prevention of cervical cancer rests significantly on whether communities are aware of cervical cancer, its risk factors and the prevention methods available. The success of secondary prevention through screening programmes also rests partly on communities understanding the reasons and need for screening.

#### Access to and availability of information in Namibia

In Namibia, knowledge levels varied depending on the location. Knowledge levels were higher in Windhoek, the capital city, where some women interviewed noted that there were pamphlets on cervical cancer at the local healthcare clinics. Some of the women interviewed complained about the inaccessibility of pamphlets on cervical cancer in local languages.

However, knowledge levels were particularly low in Okahandja. Most of the women interviewed in Okahandja were HIV-negative, which may be a factor in the low levels of knowledge among the participants. A number of women suggested that cervical cancer was seen as being associated with HIV and thus only women living with HIV were at risk of cervical cancer.

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<sup>167</sup>Rep. of Bots., Ministry of Health, Family Health Division, *Policy Guideline and Service Standards: Sexual and Reproductive Health* at 55.

<sup>168</sup>*Id.* at 58.

<sup>169</sup>Ntekim, *Cervical Cancer in SSA*, *supra* note 141, at 62.



There was a significant amount of misinformation regarding cervical cancer in Namibia. Most of the young women interviewed reported being informed by healthcare workers that contraceptives caused cervical cancer or were a risk factor for cervical cancer. Some believed the healthcare workers informed them of this to discourage young women from accessing contraceptives. One participant said:

They tell us that at the clinic. They say those [contraceptives] are very bad, especially for young people. They cause all sorts of problems, including cervical cancer. I don't know maybe they just want to discourage us.<sup>170</sup>

Another indicated:

You see I look 16 instead of 23. So, they think I am very young. The nurse asked me why I wanted the [contraceptives]. She said did I know that it can cause me unnecessary stomach problems and cancers and I can have problems having children later on in life... I do take the [contraceptives], but when I went there first to ask about it they were not pleased. I tell you, she was frowning the whole time... I would get them from the pharmacy if I had money but I hear you need a prescription.<sup>171</sup>

The linking of cervical cancer with contraceptives, if used to discourage young women from accessing family planning methods, is troubling as it entrenches the existing stigma young women reported they faced when trying to access services at the family planning clinic. One woman reported that nurses will attempt to embarrass young women out of the clinic by making loud disapproving comments while the young woman waits in the queue. The stigma facing young women at family planning clinics affects their ability to access cervical cancer services, as screening services are generally located in the family planning section of health facilities in Namibia.

### **Access to and availability of information in Zambia**

Awareness of accurate information on cervical cancer was significantly higher in Lusaka, the capital city, than in Chipata, a small town far from a major city. Several women in the Chipata groups indicated that they had never heard about cervical cancer before and not a single participant had ever heard the term HPV before. In Chipata, a number of women mistakenly thought that cervical cancer was caused by sleeping with an uncircumcised man.

Those women who had some awareness of cervical cancer primarily obtained it through verbal means, such as health talks at the ART clinic; community health workers; friends; and the media, particularly television or radio. In Lusaka, routine health talks by peer educators at local primary health facilities generally include information on cervical cancer. However, this is not the case in Chipata, possibly contributing to the low awareness levels there. Many women reported having learned about cervical cancer while waiting in lines at the local primary health facility and through their support groups. Women who did not regularly access services at the local primary health facility or were not in support groups were unlikely to have knowledge about cervical cancer.

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<sup>170</sup>Quote from Participant, Windhoek 2 Focus Group Discussion, in Windhoek, Namib. (Jan. 31, 2012).

<sup>171</sup>Quote from Participant, Windhoek 2 Focus Group Discussion, in Windhoek, Namib. (Jan. 31, 2012).

There appears to be little in the way of printed matter on cervical cancer in Zambia. Only one participant stated that she had seen a pamphlet on cervical cancer. Other participants indicated that they were not aware of any posters on cervical cancer in their local clinics. One participant noted: “It’s all on HIV. Even at the maternity [section], it’s on [prevention of mother-to-child transmission] and things like that... I can’t say I have seen posters on cervical cancer... and I go there every month almost”.<sup>172</sup>

A number of non-governmental organisations, such as the Treatment Advocacy and Literacy Campaign (TALC) and Breakthrough Cancer Trust (BCT), are raising awareness of cervical cancer outside of the health facilities, but it appears most of the awareness-raising occurs in Lusaka.<sup>173</sup>

### **Access to and availability of information in southern Africa**

Several studies have shown poor knowledge of cervical cancer throughout southern Africa, cutting across different literacy levels.<sup>174</sup> A study in Malawi found low levels of knowledge regarding cervical cancer in Mulanje, especially with respect to the need for cervical cancer screening.<sup>175</sup>

Without adequate information on the disease, the associated risk factors and prevention measures, women are unable to make decisions to take preventative measures to minimise their risk of getting the disease.

### **3.2.2 Vaccines**

Prevention of infection with HPV through vaccination has the potential to be the most effective primary prevention method available. The benefits of HPV vaccination would be greatest if implemented as part of the national immunisation programme. HPV vaccines are currently not widely available in the public sector in southern African countries. Neither Namibia nor Zambia currently provides for affordable access to HPV vaccination through the public health system.

### **Vaccines in Namibia**

Both vaccines are licensed in Namibia.<sup>176</sup> It appears HPV vaccines are not available for free through government-funded health facilities, however, the HPV vaccine is well-marketed in the private sector as a significant number of women interviewed were aware of the vaccine. Many said they had heard about it in the media or had seen a billboard advertising the vaccine. Among those women who were aware of the vaccine, knowledge of how the vaccine is administered was high.

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<sup>172</sup>Quote from Participant, Matero Focus Group Discussion, in Lusaka, Zam. (Dec. 1, 2011).

<sup>173</sup>Treatment Advoc. and Literacy Camp. & Breakthrough Cancer Tr., Remarks at the Meeting of the Zamb. AIDS Law Res. & Advoc. Network (Oct. 12, 2011).

<sup>174</sup>Ntekim, *Cervical Cancer in SSA*, *supra* note 141, at 57-59; Moodley, *supra* note 14, at 12. **See also** Louie et al., *supra* note 5, at 1287.

<sup>175</sup>Victoria K. Fort et al., *Barriers to Cervical Cancer Screening in Mulanje, Malawi: A Qualitative Study*, 5 *PATIENT PREFERENCE & ADHERENCE* 125, 127-30 (2011).

<sup>176</sup>*Global HPV Vaccine Licensure Status: June 2011*, TECHNET21: TECHNICAL NETWORK FOR STRENGTHENING IMMUNIZATION SERVICES (July 1, 2011), available at <http://www.technet21.org/index.php/documents/download-document/1286-global-hpv-vaccine-licensure-status-june-2011.html>.

Several participants stated that they had received the HPV vaccine, having been told about the vaccine by their general medical practitioners. It was confirmed by several participants that the out-of-pocket cost for the vaccine is between N\$400-600 for each of the three doses. They all said their medical aid had covered all or most of the cost.

While participants seemed to understand that the vaccine was more effective when given at a younger age, there was a lack of clarity over whether the vaccines were safe in older women and women living with HIV. Three of the participants who reported being vaccinated during the field research were younger women, although all over 18 years. However, one of the women who reported having recently received the vaccination was in her late thirties, and has three children.<sup>177</sup>

There is a need for awareness raising and government-issued guidelines providing recommendations on who should receive the vaccine, and at what age to ensure that women can make informed decisions on whether to access the vaccine.

### **Vaccines in Zambia**

Zambia has licensed Gardasil for use.<sup>178</sup> However, none of the participants in the study, neither in Lusaka nor Chipata, were aware of either vaccine as a means of preventing infection with certain high-risk types of HPV.

In the 2011 Ministry of Health Action Plan, resources were allocated for the “implementation of feasibility for HPV vaccine in Lusaka”.<sup>179</sup> Possibly due to this priority setting by government, Zambia reportedly received vaccines for cervical cancer from international donors as of February 2012.<sup>180</sup> The vaccines are expected to be used to vaccinate 6,000 school age girls in urban Lusaka and Masaiti, a rural area in the Copperbelt.<sup>181</sup>

### **Vaccines in southern Africa**

In terms of HPV vaccine licensure, six countries in southern Africa have licensed at least one of the vaccines. Four countries have failed to license either vaccine. However, very few countries have introduced an HPV vaccine for free in the public health system in Africa as a whole.<sup>182</sup> In the southern Africa region, in addition to Zambia, described above, Lesotho reportedly is rolling out a free HPV vaccination program throughout the country.<sup>183</sup> Table 1 below shows the HPV vaccine licensure status of the region.<sup>184</sup>

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<sup>177</sup>Windhoek 1 Focus Group Discussion, in Windhoek, Namib. (Jan. 31, 2012).

<sup>178</sup>*Global HPV Vaccine Licensure Status: June 2011*, *supra* note 176.

<sup>179</sup>Zam. MOH, *2011 Action Plan*, *supra* note 159, at 49.

<sup>180</sup>Mubanga Nondo-Chitambala, *Cancer Vaccine: Hope for Zambian Women*, *TIMES OF ZAMBIA* (Jan 25, 2011), available at <http://allafrica.com/stories/201201251002.html>.

<sup>181</sup>*Id.*

<sup>182</sup>WHO, *HPV IN AFRICA 2010*, *supra* note 2, at 50.

<sup>183</sup>M15 Million Earmarked for Campaign Against Cervical Cancer, *LESOTHO NEWS* (Jan. 16, 2012), available at [http://www.gov.ls/articles/2012/millions\\_earmarked\\_for\\_campaign\\_against\\_cervical\\_cancer.php](http://www.gov.ls/articles/2012/millions_earmarked_for_campaign_against_cervical_cancer.php). In Africa Rwanda and Uganda have also launched HPV vaccination programmes. **See** CERVICAL CANCER ACTION, *Progress in Cervical Cancer Prevention: The CCA Report Card 9* (2012), available at [http://www.cervicalcanceraction.org/pubs/CCA\\_reportcard\\_low-res](http://www.cervicalcanceraction.org/pubs/CCA_reportcard_low-res).

<sup>184</sup>Adapted from *Global HPV Vaccine Licensure Status: June 2011*, *supra* note 176; WHO, *HPV IN AFRICA 2010*,

**Table 1: HPV vaccine licensure status in the region**

None Licensed or no information available	Merck's Gardasil® ONLY	GlaxoSmith-Kline's Cervarix™ ONLY	Both Licensed
Angola Mozambique Swaziland Zimbabwe	Botswana Lesotho Malawi Zambia		DRC Namibia South Africa

Currently, the two HPV vaccines are much more expensive on average than vaccines for other illnesses, making them prohibitively expensive for low-resource countries unless acquired through donors.<sup>185</sup> However, in June 2011, Merck announced it would provide Gardasil to the Global Alliance for Vaccines and Immunisation (GAVI), which funds vaccines for children in the poorest countries, for US\$5 per dose, a nearly 70% reduction from the lowest public price at the time.<sup>186</sup> In November 2011, the GAVI Board invited eligible countries to apply for funding for Gardasil.<sup>187</sup> Eligibility for GAVI support is determined by national income. Six southern African countries—the Democratic Republic of Congo (DRC), Lesotho, Malawi, Mozambique, Zambia, and Zimbabwe—are eligible for GAVI vaccine support.<sup>188</sup> Angola, Botswana, Namibia, South Africa, and Swaziland are not GAVI-eligible.<sup>189</sup> It is unclear whether any GAVI-eligible country in southern Africa has applied to GAVI for Gardasil.

### 3.2.3 Screening

Screening is a critical aspect of cervical cancer prevention and will remain so even if vaccine availability drastically improves over the next few years. Screening is not just important for prevention, but is also the gateway to treatment. Lack of availability of screening services is the primary reason for the disparity in incidence and mortality rates between the developed and developing world.<sup>190</sup> Access to screening in Zambia is determined by geographical location with very little if any availability of screening services for those outside of Lusaka. In Namibia, while cervical cancer services seem to generally be available, access is hindered by factors such as the lack of prioritisation of cervical cancer screening by health workers.

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*supra* note 2 at 50; **and** WHO/ICO, HUMAN PAPILLOMAVIRUS AND RELATED CANCERS, COUNTRY REPORTS FOR ANGOLA, BOTSWANA, THE DEMOCRATIC REPUBLIC OF CONGO, LESOTHO, MALAWI, MOZAMBIQUE, NAMIBIA, SWAZILAND, ZAMBIA AND ZIMBABWE (2010), available at <http://apps.who.int/hpvcentre/statistics/dynamic/ico/SummaryReportsSelect.cfm>.

<sup>185</sup>The vaccines currently cost about \$375 for the full series of injections (not including the doctor's fee or the cost of giving the injections) in the U.S. **See** AMERICAN CANCER SOCIETY, *Cervical Cancer* (Mar. 14, 2012), available at <http://www.cancer.org/acs/groups/cid/documents/webcontent/003094-pdf.pdf>.

<sup>186</sup>GAVI ALLIANCE, *supra* note 1.

<sup>187</sup>*Id.*

<sup>188</sup>GAVI ALLIANCE, *Countries Eligible for GAVI Support* (2011), available at <http://www.gavialliance.org/support/apply/countries-eligible-for-support/>.

<sup>189</sup>*Id.*

<sup>190</sup>Chirenje, *supra* note 12, at 131.

### Availability of and access to screening services in Namibia

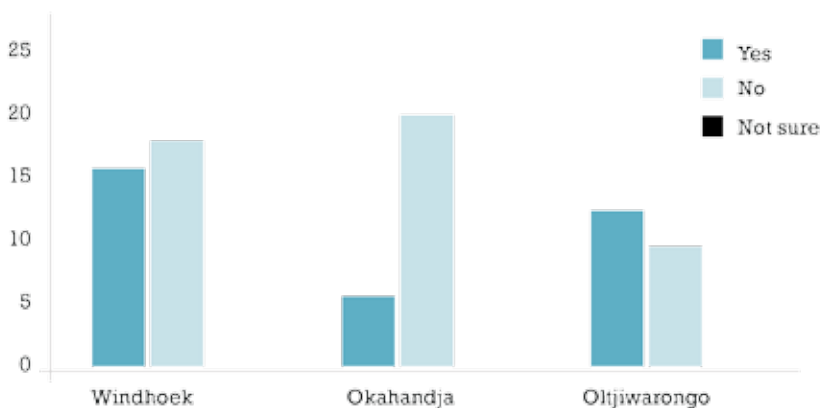
Namibia's Family Planning Policy provides for all health centres and clinics to offer Pap smear screening.<sup>191</sup> This is implemented in Windhoek, where screening services are generally accessible at primary health facilities in the family planning section of the clinic. However, regular screening services were reportedly not available in Okahandja. Participants from Okahandja indicated that cervical cancer screening was available as part of regular screening drives, but not every day at the family planning clinic.

The lack of regular services impacted the number of women who accessed screening. Of the participants in Okahandja who had been screened, none accessed services through the public health sector in Okahandja. Those who reported that they had been screened indicated that they had accessed screening in the private sector.

In Otjiwarongo, participants indicated that screening was available at the district hospital.

Figure 1 illustrates the number of women interviewed who indicated that they had been screened for cervical cancer in Namibia.

**Figure 1: Have you ever had cervical cancer screening?**



The women interviewed in Namibia also reported that healthcare workers placed a low priority on cervical cancer screening, making it less likely that women will access the service. One participant stated: “They don’t like doing Pap smears. It’s like it’s a burden to them. They will tell you: we are busy; I have other important things to do. It’s like [a] Pap smear is at the lowest end in terms of priorities”.<sup>192</sup>

Another woman stated: “Screening should be like HIV tests. You should go to the clinic whenever and they just do it. Right now it’s like it’s not important. The nurses don’t treat it like it’s important. Maybe that’s why, we people, we also don’t take it that seriously”.<sup>193</sup>

<sup>191</sup>Rep. of Namib., Ministry Health and Soc. Serv., *Family Planning Policy* (1995), at 18, available at <http://www.healthnet.org.na/documents/policies/Family%20Planning%20Policy.pdf>.

<sup>192</sup>Quote from Participant, Windhoek 1 Focus Group Discussion, in Windhoek, Namib. (Jan. 31, 2012).

<sup>193</sup>Quote from Participant, Okahandja 2 Focus Group Discussion, in Okahandja, Namib. (Feb. 1, 2012).

Some participants reported that the lack of adequate hygiene in the clinics made them reluctant to access screening services. One participant stated:

Those gowns are just passed on from person to person. People are sitting in them naked, waiting for their turn and when you are finished, you hang them back and the next person picks it up. Personally when I think of it, it really puts me off going for the Pap smear. Even those beds they don't disinfect them after each person... [nor] do they put a disposable mat...<sup>194</sup>

The screening method generally used in Namibia is the conventional Pap smear screening. Using this screening method created a number of obstacles for women. Participants complained about the delay in obtaining Pap smear test results or the results being lost. Pap smear screening also required some participants to return to the health facility on several occasions for their results. Some participants eventually gave up on obtaining their results.

The delay in obtaining results appears to have reduced significantly over the past few years. Recently, more laboratories in Namibia have reportedly begun processing Pap smears, resulting in reduced delays in patients obtaining their results. One participant in Windhoek, who works with the pathology services, confirmed that until recently all Pap smear samples from across the country were sent to Windhoek for processing. Nurses interviewed in Otjiwarongo confirmed that they were now able to have Pap smears processed locally, as opposed to having to send them to Windhoek. Due to these improvements, the current reported time for patients to obtain results for Pap smears was approximately four to six weeks.

However, even where infrastructural concerns, such as laboratories are addressed, barriers to effective cervical cancer care remain due primarily to the use of the Pap smear screening method. Follow-up remains a problem in Namibia, given that screening requires multiple visits. In Windhoek, participants reported that women seeking a Pap smear screening had to make an appointment, which necessitated multiple trips to the health facility, one trip to make the appointment and then another trip the day of the appointment. Women were required to wait between three weeks to two months from the date of seeking an appointment to the actual appointment date. Reportedly, immediate screening only occurs when there is a doctor's referral. In Windhoek, the Namibia Planned Parenthood Association (NAPPA), a non-governmental organisation, reportedly offers free immediate Pap smear screening, but it appears no such service is available in the government-funded public health system.

#### **Availability of and access to screening services in Zambia**

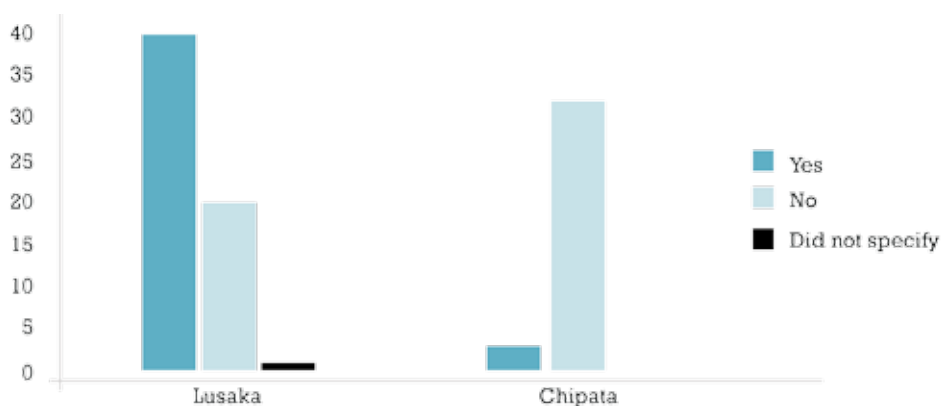
Screening services are generally available in Lusaka at primary public health facilities and are integrated into HIV services. However, outside of Lusaka, access to screening was reported to be almost non-existent. Very few women in Chipata had been screened for cervical cancer, as opposed to Lusaka where a majority of women reported having been screened.

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<sup>194</sup>Quote from Participant, Windhoek 1 Focus Group Discussion, in Windhoek, Namib. (Jan. 31, 2012).

Figure 2 illustrates the number of women interviewed who indicated that they had been screened for cervical cancer in Zambia.

**Figure 2: Have you ever had cervical cancer screening?**



Cervical cancer screenings, primarily using the visual inspection method, are available in Lusaka. Four out of the five focus groups reported that screening services were available at their nearest local clinic for free. The only group that reported having to travel a significant distance to access screening services was the Kalingalinga group, located in a semi-rural settlement area near Lusaka, because the clinic closest to them did not offer cervical cancer screening.<sup>195</sup>

However, despite the availability of screening services in the greater Lusaka area, participants reported barriers to accessing those services. Generally, women reported that screening was not offered every day at the clinics, due in some cases to a lack of staff. In Lusaka, participants reported that one nurse was responsible for screening at several clinics, resulting in screening being available only on specific days of the working week. In addition, participants indicated that only a limited number of women could be screened per day, resulting in many women being turned away from the clinic. One participant noted:

No, they only screen 10 people per day, you see, and only before 12pm. So, if you arrive late, you are told to come back another day. Or if there are too many of you there, she counts one to 10, then to the rest she says come back. That's usually the next week. So, sometimes it's discouraging. The next day if you are not in the first 10, the line is cut again and you go back again... if you are sent back two/three times, you think, why bother.<sup>196</sup>

Screening services outside of Lusaka are severely limited. The Centre for Infectious Disease Research in Zambia (CIDRZ) reported that in February 2011, of the 17 clinics in PEPFAR-funded primary health sites in Zambia offering cervical cancer screening services,

<sup>195</sup>Participants indicated that the closest clinic offering screening for them was Chingwere Clinic. Transportation costs to the Chingwere Clinic were approximately 6,500 Zambian kwacha (approximately US\$1.25). Participants in the four other groups were generally within walking distance or one taxi ride to their nearest screening facility.

<sup>196</sup>Quote from Participant, Kanyama Focus Group Discussion, in Lusaka, Zam. (Nov. 30, 2011).

only five were outside of Lusaka. CIDRZ also indicated that there were additional mobile screening services available in other areas of Zambia.<sup>197</sup>

In Chipata, screening services were only available at the Chipata General Hospital, not the local health clinic where most women access medical services. In addition, there were numerous obstacles to accessing screening services at Chipata General Hospital. Screening services are reportedly only obtainable through a referral from medical personnel and, due to staff shortages, screening services were not always available at Chipata General Hospital, requiring women to have to return repeatedly to obtain screening. One woman explained how she was eventually forced to travel to St. Francis Mission Hospital, 45 kilometres away, to obtain medical services. She stated:

Here, in Chipata, they couldn't help me... I would come and meet this doctor, then another doctor, for two months until a nurse advised me: please talk to the doctor, so you can be given a referral letter to St. Francis. But when I saw the doctor, he said no St. Francis, it's just a clinic [compared] to Chipata General.<sup>198</sup>

Another obstacle to accessing screening in Chipata is the Chipata General Hospital's use of Pap smear screening. Pap smear screening requires multiple visits by the patient, a doctor to perform the screening, and the use of laboratory facilities. All of these factors can often delay the screening and the results. One participant recounted:

Let me tell you my process here at Chipata took about two months. That room 14, which my sister is talking about, it's really, I don't know, for you to meet that doctor. I used to find people smelling on the line. It's just that for me I realised fast[er] to go to... [St. Francis Mission Hospital]. I was talking to people and they were saying I have been coming to this room 14 for six months now for them to be referred, to get those results of that biopsy. Me, I just left all the papers [at] Chipata General Hospital and started a new process there at St. Francis.<sup>199</sup>

To the extent screening is made more easily available in Chipata, it is often done as part of time-limited screening drives. Several participants in the Chipata groups indicated that there had been a mobile clinic as part of a Centre for Infectious Disease Research in Zambia (CIDRZ) project, which had been in Chipata around June and July 2011. However, none of the women interviewed had accessed the screening during the mid-2011 screening drive. Participants noted that they had not been told in advance about the screening. In addition, a screening drive at Chipata General Hospital leading up to the 2012 World Cancer Day Commemorations had screened 387 women for cervical cancer within a few days.<sup>200</sup> However, these sporadic screening drives do not provide women the needed accessibility to be screened on a regular basis.

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<sup>197</sup>CIDRZ, *Cervical Cancer Screening*, available at [http://www.cidrz.org/cervical\\_cancer\\_screening](http://www.cidrz.org/cervical_cancer_screening).

<sup>198</sup>Quote from Participant, Chipata 1 Focus Group Discussion, in Chipata, Zam. (Dec. 6, 2011).

<sup>199</sup>Quote from Participant, Chipata 1 Focus Group Discussion, in Chipata, Zam. (Dec. 6, 2011).

<sup>200</sup>Christopher Miti, *MoH Commissions Cancer-Screening Centres in Chipata, Katete*, THE POST ONLINE (Zam.) (Feb. 5, 2012, 1:01 PM), available at [http://www.postzambia.com/post-read\\_article.php?articleId=24958](http://www.postzambia.com/post-read_article.php?articleId=24958).



### **Availability of and access to screening services in southern Africa**

Most countries in southern Africa have a cervical cancer screening programme either administered by the government, non-governmental organisations and institutions, or a combination of the two. South Africa and Botswana both have screening programmes which rely on laboratories to examine samples collected from a woman's cervix.<sup>201</sup> Malawi and Mozambique reportedly introduced national screening programmes using the visual inspection method.<sup>202</sup> Angola and Lesotho have initiated pilot screening projects using the visual inspection method.<sup>203</sup> As of 2009, Swaziland did not have a government-run programme, but a non-governmental organisation offers cervical cancer screening on a small scale in the two main cities.<sup>204</sup>

However, most screening programmes in southern Africa fail to reach most women in the country. Even in South Africa, which has had a screening programme since 2001, screening services are not available throughout the country and no proper assessment of its impact is available.<sup>205</sup> In 2010, in Malawi, only 63 out of 540 health facilities were providing VIA services.<sup>206</sup>

The failure to reach a significant majority of women is due in part to the fact that most screening activities in southern Africa are part of pilot or research projects, which by their very nature are time limited.<sup>207</sup>

## **3.3 Treatment services**

Treatment services should be available for treatment of pre-cancerous lesions as well as for invasive cancer. The type of treatment needed will depend on the grade of the pre-cancerous lesions or the stage of the cancer.

### **3.3.1 Treatment for pre-cancerous lesions**

In Zambia, services for treatment of pre-cancerous lesions are generally not available outside of Lusaka. There were also challenges in terms of women understanding the diagnosis and treatment. In Namibia, none of the women in the focus group discussions had accessed treatment services for pre-cancerous lesions.

#### **Treatment for pre-cancerous lesions in Namibia**

In Namibia, none of the participants reported having been treated for pre-cancerous lesions. Participants indicated that women with abnormal Pap smears are generally referred to a district hospital for further diagnosis and treatment if necessary. It appears that clinics do not have the capacity to provide any treatment for pre-cancerous lesions.

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<sup>201</sup>Ntekim, *Cervical Cancer in SSA*, *supra* note 141, at 51, 62.

<sup>202</sup>CERVICAL CANCER ACTION, *Progress in Cervical Cancer Prevention: The CCA Report Card*, *supra* note 183 at 9.

<sup>203</sup>*Id.*

<sup>204</sup>Sylvain Okonda et al., *The Status of Cervical Cytology in Swaziland, Southern Africa: A Descriptive Study*, CYTOJOURNAL (Aug. 6, 2009), available at <http://www.cytojournal.com/text.asp?2009/6/1/14/54916>.

<sup>205</sup>Ntekim, *Cervical Cancer in SSA*, *supra* note 141, at 51.

<sup>206</sup>PATH, *IMPROVED PREVENTION*, *supra* note 166, at 34.

<sup>207</sup>Ntekim, *Cervical Cancer in SSA*, *supra* note 141, at 52.

### **Treatment for pre-cancerous lesions in Zambia**

Treatment for pre-cancerous lesions is available and accessible in Lusaka. The primary method used to treat pre-cancerous lesions in Lusaka appears to be cryotherapy, which the women interviewed referred to as freezing. The procedure was reportedly done immediately after screening if the result was abnormal, ensuring that women would not have to return for treatment after screening. Women were asked to return after 3 to 6 months for a follow-up visit at the local primary health facility, reducing the burden of travel on women. In addition, the women who had undergone treatment for pre-cancerous lesions were the most well-informed regarding the basic facts related to cervical cancer in the focus group.

In a few cases, the single visit treatment approach was not utilised and if prevalent could result in women failing to follow up on an abnormal screening result. A few women in the Matero focus group in the greater Lusaka area, recounted that they were not immediately treated after an abnormal screening result. Instead, they were encouraged to go home and decide with their husbands if they wanted to undergo cryotherapy and return if they decided to access treatment.<sup>208</sup>

In Chipata, there was no available treatment for pre-cancerous lesions. Abnormal Pap smear results from Chipata General Hospital reportedly were referred to the National Cancer Diseases Hospital located at the University Teaching Hospital in Lusaka, requiring Chipata residents to travel to Lusaka to access treatment. It was unclear whether hospitals or facilities closer to Chipata, such as St. Francis Mission Hospital, had the capacity to do cryotherapy or any other procedure for treatment of pre-cancerous lesions.

One of the main obstacles to effective access to treatment that arose from the focus group discussions was the challenge in understanding the nature and reason for the treatment, which resulted in some cases in refusal of treatment. A number of women we interviewed opted not to receive treatment in part due to a fear of the diagnosis. Several women reported opting for alternative remedies to deal with the diagnosis.

In other cases, the lack of understanding of the treatment may have compromised its effectiveness or increased pain for patients. Some participants indicated difficulty in following post-treatment medical recommendations. One participant, who had been treated for pre-cancerous lesions in Zambia, reported that she found it difficult to abstain from sex for three months as was ordered by her medical personnel. She explained why she found it difficult as follows: “My husband simply did not get it. He thought I was being funny. So to avoid arguments, I gave in before even one month was up... It was a bit painful. I felt tender inside here, but I was ok. When I went for the review, they said I was ok”.<sup>209</sup>

One woman said the nurses had not explained properly about the discharge that occurs after cryotherapy and she was afraid the discharge meant her treatment was unsuccessful. She was afraid to go back to the health facility as she did not want to be given bad news

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<sup>208</sup>Matero Focus Group Discussion, in Lusaka, Zam. (Dec. 1, 2011).

<sup>209</sup>Quote from Participant, Kanyama Focus Group Discussion, in Lusaka, Zam. (Nov. 30, 2011).

and only returned for her necessary review when a friend informed her that the discharge after the cryotherapy was normal.<sup>210</sup>

### **Treatment for pre-cancerous lesions in southern Africa**

Hysterectomy and cone biopsy are the primary treatment options for pre-cancerous lesions. LEEP/LLETZ may be available, but often the equipment and the expertise needed to perform the procedure are limited.<sup>211</sup> In Lesotho, healthcare providers primarily use cold conization.<sup>212</sup> It was unclear whether cryotherapy was available in Lesotho.<sup>213</sup> In Malawi, cryotherapy was available at 41 out of 125 sites in 2010.<sup>214</sup> However, reaching rural women and obtaining sufficient cryotherapy units remained a challenge.<sup>215</sup>

### **3.3.2 Treatment for cancer**

Treatment for cervical cancer is an important aspect of cervical cancer management. In both Zambia and Namibia, access to treatment for cervical cancer appears to be limited to hysterectomies. In addition, structural problems such as inadequate personnel and laboratory facilities have adverse effects, which sometimes result in patients and health workers making cervical cancer management choices without adequate information or proper diagnosis.

### **Treatment for cancer in Namibia**

Participants in Namibia were unaware of the various treatment options available for cervical cancer. Of the participants who were familiar with treatment of cervical cancer, they all viewed a hysterectomy as the most common and effective way of treating cervical cancer. Very few participants were aware of further and complimentary treatment options, such as radiation or chemotherapy.

In addition, women who did access treatment often reported feeling inadequately informed regarding their diagnosis and treatment options. Some women reported feeling under pressure to have hysterectomies even before they had understood their diagnosis and had considered all treatment options because the need for intervention was often presented as urgent. In some cases, women who reported having a hysterectomy to treat cervical cancer expressed feeling fear that death was imminent unless they immediately underwent the procedure. One woman in Windhoek said, “I was cautioned that if I did not have the operation as soon as possible the results would be fatal”.<sup>216</sup> This woman had been advised that she had to have the operation within the week she was diagnosed.<sup>217</sup> Another participant in Windhoek recounted a similar experience noting that “the doctor said I had cancer. He said either they remove the uterus or I would die”.<sup>218</sup>

Among participants who were living with HIV, there was a general suspicion that

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<sup>210</sup>Matero Focus Group Discussion, in Lusaka, Zam. (Dec. 1, 2011).

<sup>211</sup>Ntekim, *Cervical Cancer in SSA*, *supra* note 141, at 60.

<sup>212</sup>PATH, IMPROVED PREVENTION, *supra* note 166, at 30.

<sup>213</sup>*Id.*

<sup>214</sup>*Id.* at 34.

<sup>215</sup>*Id.*

<sup>216</sup>Quote from Participant, Windhoek 3 Focus Group Discussion, in Windhoek, Namib. (Feb. 3, 2012).

<sup>217</sup>Windhoek 3 Focus Group Discussion, in Windhoek, Namib. (Feb. 3, 2012).

<sup>218</sup>Quote from Participant, Windhoek 1 Focus Group Discussion, in Windhoek, Namib. (Jan. 31, 2012).

cervical cancer could be used by health providers as another reason to deny women living with HIV fertility choices. Women in Windhoek particularly felt that they were offered hysterectomies as a first line of treatment for pre-cancerous lesions. One woman explained that the fact that doctors do not take time to explain the cancer stages to them fuels this suspicion. “We don’t know what is this pre-cancer. We just know cancer”.<sup>219</sup> Another woman stated:

The doctor said I had lumps and said I must take [my] uterus out if I want to live. I don’t know if it was pre-cancer or real cancer. He did not give me any other options, he just said the treatment was [that] it was best for me to remove the uterus... now with these things that have come to light, it makes you wonder, did I really need to remove my uterus? I don’t know.<sup>220</sup>

Failure to provide adequate and accurate information to patients makes it less likely that women will access treatment when it is needed.

### **Treatment for cancer in Zambia**

The National Cancer Diseases Hospital at the University Teaching Hospital (UTH) in Lusaka is the only referral hospital for advanced cervical cancer treatment in Zambia. Costs associated with travel to access the UTH, misinformation regarding treatment and cost options, and failure to follow up on referrals emerged as major obstacles to effectively accessing treatment services in Zambia.<sup>221</sup>

In Chipata, women have to travel almost 600 kilometres from Chipata to Lusaka on the bus at a cost of 130,000 Zambian kwacha (US\$25), one way, to access services at the UTH. Though an ambulance is available to take patients from Chipata General Hospital to the UTH, participants indicated that it is unreliable, and patients who are not in critical condition are often asked to delay their trips as the ambulance’s capacity is reached. Patients not officially referred from Chipata General Hospital to the UTH would have to travel on their own for a second opinion or additional treatments.

Similar obstacles were documented in Lusaka, where participants who had tried to access services at the UTH after obtaining a referral noted that the referrals required multiple appointments, raising transport costs, and making it less likely that women will access the services they need. One participant noted:

I was screened and referred to UTH. I have been going for review after review, but it was not clear whether they were doing tests or giving me treatment. It seemed like it was test after test. Eventually, I stopped going.<sup>222</sup>

In other cases, women failed to access services due to misinformation regarding the cost of treatment. One participant noted:

Some women do not go when they are referred to UTH because they think

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<sup>219</sup>Quote from Participant, Windhoek 3 Focus Group Discussion, in Windhoek, Namib. (Feb. 3, 2012).

<sup>220</sup>Quote from Participant, Windhoek 3 Focus Group Discussion, in Windhoek, Namib. (Feb. 3, 2012).

<sup>221</sup>Kapambwe, SCREENING IN ZAMBIA, *supra* note 152, at 3.

<sup>222</sup>Quote from Participant, Kamwala Focus Group Discussion, in Lusaka, Zam. (Dec. 1, 2011).

they will have to pay. But this is no longer the case, you don't pay any more unless it's very advanced and they are now doing other things. For the biopsy and freezing you don't pay. Even hysterectomy you don't pay, maybe chemotherapy and those other thing[s].<sup>223</sup>

In Chipata, delay in Pap smear results and failure to provide patients with adequate information may lead to aggressive, unneeded, and irreversible treatment. One participant in Chipata indicated that she had a hysterectomy prior to getting her biopsy results.<sup>224</sup> Due to delays in receiving pathology results, she was left with no choice but to choose a treatment option without adequate information or proper diagnosis.

I was pregnant, one month two weeks and I started bleeding, no pain... the doctor was try[ing] to clean me after that miscarriage. Then he saw something like a sore and said no, this is dangerous. We have to cut a small piece and send to Lusaka. But it was taking long, almost two months; they were not doing anything when I changed the hospital. That's when I went to Katete [St. Francis Mission Hospital]. They sent that small piece of the something to the Netherlands, but the doctors advised that the results take too long [and] that [it's] better we remove the uterus before it's too late.<sup>225</sup>

This woman indicated that the doctors advised her that the biopsy results took on average three to six months and "you can die anytime".<sup>226</sup> She noted that when the results eventually came about four months later, the doctors indicated that "the cancer was in the early stages".<sup>227</sup>

Finally, a number of women interviewed indicated that fear of the diagnosis, which was heightened after being referred to a tertiary institution like the UTH, made them reluctant to follow up on the referral. One woman reported a fear that when you are sent to the UTH things are "really bad".<sup>228</sup> Another participant noted that, "being referred to UTH is like being told you are dying".<sup>229</sup> Another recounted that "[the staff at the UTH] removed my aunt's placenta when she went there, but she still died. So I think if they refer you there you should be worried".<sup>230</sup> In the initial CIRDZ project, over half of the women referred to the UTH for evaluation failed to comply.<sup>231</sup>

In addition to the above-mentioned obstacles, there was little awareness of the range of treatment options and side effects of treatment among all women interviewed in Zambia. All participants in Zambia reported that the pervasive belief among women was that a

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<sup>223</sup>Quote from Participant, Kanyama Focus Group Discussion, in Lusaka, Zam. (Nov. 30, 2011).

<sup>224</sup>In the discussions the participants tended to use the terms "sterilisation", "hysterectomy", and "removal of the uterus or womb" interchangeably. It appears however, that in most cases where they were speaking in the context of cervical cancer management they were referring to hysterectomies as opposed to sterilisation by closing off the Fallopian tubes only.

<sup>225</sup>Quote from Participant, Chipata 1 Focus Group Discussion, in Chipata, Zam. (Dec. 6, 2011).

<sup>226</sup>Quote from Participant, Chipata 1 Focus Group Discussion, in Chipata, Zam. (Dec. 6, 2011).

<sup>227</sup>Quote from Participant, Chipata 1 Focus Group Discussion, in Chipata, Zam. (Dec. 6, 2011).

<sup>228</sup>Quote from Participant, Chipata 1 Focus Group Discussion, in Chipata, Zam. (Dec. 6, 2011).

<sup>229</sup>Quote from Participant, Chipata 1 Focus Group Discussion, in Chipata, Zam. (Dec. 6, 2011).

<sup>230</sup>Quote from Participant, Matero Focus Group Discussion, in Lusaka, Zam. (Dec. 1, 2011).

<sup>231</sup>Mulindi H. Mwanahamuntu et al., *Advancing Cervical Cancer Prevention Initiatives in Resource-Constrained Settings: Insights from the Cervical Cancer Prevention Program in Zambia*, 8 PLOS MED., May 2011, at 2.

hysterectomy was the most common and effective way of treating cervical cancer. Some participants felt that some women avoided screening because they were afraid they would be subjected to a hysterectomy. One woman indicated that a nurse had told her that the removal of the uterus is the best prevention against cancers and uterine problems which are common to women living with HIV.<sup>232</sup> Very few participants were aware of any other treatment options, such as radiation or chemotherapy.

Those who were aware of alternative treatment to hysterectomy were still unaware of the fertility implications of alternative treatments such as radiation.

### **Treatment for cancer in southern Africa**

The treatment of invasive cervical cancer continues to be a major challenge in many sub-Saharan African countries, due to the lack of skilled providers, radiotherapy services, and surgical facilities.

Management of women with invasive cervical cancer requires a multidisciplinary approach, requiring the expertise of gynecologists; radiation oncologists; medical oncologists; pathologists; medical physicists; technicians; nurses; and counsellors. However, many of the countries in the region do not have access to all of the specialists needed.<sup>233</sup> In 2009, there were five gynecologists, one oncologist, three cytotechnicians, and one pathologist in Swaziland's government health institutions.<sup>234</sup> In Lesotho, there is a dearth of specialists such that women with advanced cervical cancer are referred to South Africa for treatment.<sup>235</sup>

Treatment approaches involving radiation and chemotherapy are not widely available in sub-Saharan Africa. According to a 2008 study, less than half of the countries in sub-Saharan Africa provided radiotherapy.<sup>236</sup> Furthermore, though the number of radiotherapy units increased significantly in the past decade, most of the increase took place in countries with existing capability.<sup>237</sup>

## 3.4 Palliative care services

Comprehensive palliative care is an important component of cervical cancer management. Failure to plan and provide adequately for cervical cancer prevention and treatment services often results in the needless suffering of women from severe and prolonged physical pain.<sup>238</sup>

Most cancer patients in Africa report pain as one of their primary symptoms as most patients only approach medical facilities once the cancer is advanced.<sup>239</sup> In a survey

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<sup>232</sup>Kanyama Focus Group Discussion, in Lusaka, Zam. (Nov. 30, 2011).

<sup>233</sup>Ntekim, *Cervical Cancer in SSA*, *supra* note 141, at 60.

<sup>234</sup>Okonda, *supra* note 204.

<sup>235</sup> PATH, *IMPROVED PREVENTION*, *supra* note 166, at 30.

<sup>236</sup>Odendal, *supra* note 14, at 9.

<sup>237</sup>*Id.* at 9.

<sup>238</sup>Cain, *Women's options*, *supra* note 65, at 141.

<sup>239</sup>Ntekim, *Cervical Cancer in SSA*, *supra* note 141, at 61.

of terminally ill patients in five countries in Africa the greatest need expressed by the patients was pain relief.<sup>240</sup>

The palliative care needs of cervical cancer patients are not being met in Namibia or Zambia. Neither country has a comprehensive national palliative care policy. Research found that in both Namibia and Zambia only doctors could prescribe morphine and it was only available through hospitals, making it inaccessible for a majority of women dying from cervical cancer.<sup>241</sup>

Access to palliative care services was not specifically explored during the focus group discussions, but a number of participants referred to the role of home-based care in the context of cervical cancer management.

### **Palliative care in Namibia**

Namibia does not have a comprehensive national palliative care policy. A few policies do mention palliative care, but they do not provide any clear guidance on how palliative care should be implemented. For example, the Community-Based Health Care Policy notes that home-based care encompasses palliative care, among others, but does not provide any additional guidance on how such care should be accessed or administered.<sup>242</sup>

As of 2009, Namibia was providing enough pain medication to address the pain of less than 11% of those in need.<sup>243</sup> It is unlikely that most women living with advanced cervical cancer are able to access the necessary pain relief.

### **Palliative care in Zambia**

Many of the participants interviewed were aware of the need for palliative care for women with advanced cervical cancer. A few indicated that they acquired this information from their work in home-based care, where they provided their clients with cervical cancer sanitary wear and disinfectant. Some care givers for example spoke of people being given pain killers to relieve the intense pain experienced with advanced cervical cancer.<sup>244</sup>

However, it is unlikely that women in Zambia with advanced cervical cancer are having their pain-relief needs met. In 2009, Zambia's consumption of medication to provide pain relief only addressed the pain of 1.9% of those who needed the medication.<sup>245</sup> Part of this gap could be addressed if Zambia were to institute a national palliative care policy. Currently, no such policy exists. There are policies that discuss palliative care with respect to specific diseases such as HIV – such as the National Guidelines on Management

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<sup>240</sup>Cecilia Sepulveda et al., *Quality Care at the End of Life in Africa*, 327 *BMJ* 209, 210 (2003).

<sup>241</sup>RICHARD HARDING ET AL., PAIN RELIEVING DRUGS IN 12 AFRICAN PEPFAR COUNTRIES: MAPPING CURRENT PROVIDERS, IDENTIFYING CURRENT CHALLENGES, AND ENABLING EXPANSION OF PAIN CONTROL PROVISION IN THE MANAGEMENT OF HIV/AIDS at 19, 21 (2007), available at <http://www.theworkcontinues.org/displaypagedoc.asp?id=1523>.

<sup>242</sup>Rep. of Namib., Ministry Health & Soc. Serv., *National Policy on Community Based Health Care* (2007).

<sup>243</sup>GLOBAL ACCESS TO PAIN RELIEF INITIATIVE, ACCESS TO PAIN RELIEF: A COUNTRY SNAP SHOT, NAMIBIA (2012), available at <http://www.gapri.org/sites/default/files/ttp/reports/Namibia.pdf>.

<sup>244</sup>Quotes from Participants, Chipata 1 Focus Group Discussion, in Chipata, Zam. (Dec. 6, 2011).

<sup>245</sup>GLOBAL ACCESS TO PAIN RELIEF INITIATIVE, ACCESS TO PAIN RELIEF: A COUNTRY SNAP SHOT, ZAMBIA (2012), available at <http://www.gapri.org/sites/default/files/ttp/reports/Zambia.pdf>.

and Care for People Living with HIV and AIDS.<sup>246</sup> There are also policies that focus on palliative care as part of other services – such as the Minimum Standards for Community and Home Based Care Organisations in Zambia – which discusses pain management in the context of home-based care.<sup>247</sup> But none of these policies comprehensively address access to palliative care for all illnesses, including cervical cancer, which is critical to ensuring that palliative care is available for all women with advanced cervical cancer.

### **Palliative care in southern Africa**

There is a lack of commitment by southern African countries to ensure the availability of medicines that can relieve pain.<sup>248</sup> All countries in the region have a very low average consumption of pain-relief drugs.<sup>249</sup> In 2008, the mean consumption of morphine – the recommended opioid for pain management – in Africa was only 0.33mg compared with the global mean of 5.98mg.<sup>250</sup>

Even where countries have ensured the availability of morphine, only 14 African nations have oral morphine. Availability of oral morphine makes it easier for patients to self-administer their pain relief where medical personnel are limited. All other countries in Africa have injectable morphine which is primarily used to treat acute pain in hospital settings.<sup>251</sup> In addition, most countries in southern Africa do not have comprehensive national palliative care policies, resulting in lower awareness of the need for palliative care.<sup>252</sup>

## 3.5 Conclusion

Very few countries in southern Africa are effectively addressing cervical cancer. Almost no countries have comprehensive cervical cancer policies and few ensure equitable access to cervical cancer services, including vaccines, screening services, treatment for pre-cancerous lesions and invasive cancer, and palliative care. To ensure women do not needlessly die from cervical cancer, countries must issue comprehensive national policies on cervical cancer and make sure that cervical cancer services are accessible and available in the public health system.

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<sup>246</sup>Government of Zam., *National Guidelines for PLWHA*, *supra* note 162, at 67–79.

<sup>247</sup>Rep. of Zam., Nat'l AIDS Council, *Zambia National Minimum Standards for Community and Home-Based Care Organisations*, at 1, 20, 29, 37, 38 (2007).

<sup>248</sup>HUMAN RIGHTS WATCH, "PLEASE, DO NOT MAKE US SUFFER ANYMORE.. ": ACCESS TO PAIN TREATMENT AS A HUMAN RIGHT 24 (2009) [hereinafter HRW REPORT ON PAIN TREATMENT], available at [http://www.hrw.org/sites/default/files/reports/health0309webwcover\\_1.pdf](http://www.hrw.org/sites/default/files/reports/health0309webwcover_1.pdf).

<sup>249</sup>INTERNATIONAL NARCOTICS CONTROL BOARD, REPORT OF THE INTERNATIONAL NARCOTICS CONTROL BOARD ON THE AVAILABILITY OF INTERNATIONALLY CONTROLLED DRUGS: ENSURING ADEQUATE ACCESS FOR MEDICAL AND SCIENTIFIC PURPOSES 67–68 (2010), available at [http://www.incb.org/pdf/annual-report/2010/en/supp/AR10\\_Supp\\_E.pdf](http://www.incb.org/pdf/annual-report/2010/en/supp/AR10_Supp_E.pdf).

<sup>250</sup>*Palliative Care in Africa: The Need*, AFRICAN PALLIATIVE CARE ASSOCIATION (June 12, 2012), available at [http://www.africanpalliativecare.org/index.php?option=com\\_content&view=article&id=41&Itemid=26](http://www.africanpalliativecare.org/index.php?option=com_content&view=article&id=41&Itemid=26).

<sup>251</sup>HRW REPORT ON PAIN TREATMENT, *supra* note 248, at 24.

<sup>252</sup>*Palliative Care in Africa: The Need*, *supra* note 250.



## 4. International and Regional Human Rights Obligations

There are currently adequate medical and scientific tools available to significantly reduce the incidence of pain and mortality caused by cervical cancer in any resource setting.<sup>253</sup> In addition to the medical tools available to address cervical cancer, southern African countries are obligated under international and regional law to provide such services and tools to address cervical cancer.

The African Commission on Human and Peoples' Rights (African Commission) has highlighted that international treaties, even where they are not part of domestic law and therefore not directly enforceable in the national courts, "nonetheless impose obligations on State Parties".<sup>254</sup> It is also generally accepted that when countries ratify an international treaty they demonstrate their willingness to be bound by the provisions of such a document and to act in accordance with its principles.<sup>255</sup>

This section provides an overview of the international and regional law obligations of governments in southern Africa to provide medical and other cervical cancer-related services.

The most relevant international and regional human rights treaties are as follows:

- the International Covenant on Civil and Political Rights (ICCPR),<sup>256</sup>
- the International Covenant on Economic, Social and Cultural Rights (ICESCR),<sup>257</sup>
- the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW),<sup>258</sup>

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<sup>253</sup>Cain, *Women's options*, *supra* note 65, at 143.

<sup>254</sup>*Legal Resources Found. v. Zambia, Afr. Comm'n on Hum. & Peoples' Rts.*, Communication No. 211/98, para. 60 (2001).

<sup>255</sup>OFFICE OF THE UNITED NATIONS HIGH COMMISSIONER FOR HUMAN RIGHTS, *THE UNITED NATIONS HUMAN RIGHTS TREATY SYSTEM: AN INTRODUCTION TO THE CORE HUMAN RIGHTS TREATIES AND THE TREATY BODIES* 23 (2005).

<sup>256</sup>International Covenant on Civil and Political Rights, opened for signature Dec. 16, 1966, 99 U.N.T.S. 171 (entered into force Mar. 23, 1976) [hereinafter ICCPR].

<sup>257</sup>International Covenant on Economic, Social and Cultural Rights, opened for signature Dec. 16, 1966, 993 U.N.T.S. 3 (entered into force Jan. 3, 1976) [hereinafter ICESCR].

<sup>258</sup>Convention on the Elimination of All Forms of Discrimination Against Women, opened for signature Dec. 18,

- the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT);<sup>259</sup>
- the African Charter on Human and People's Rights (African Charter);<sup>260</sup> and
- the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (African Women's Protocol).<sup>261</sup>

Other treaties such as the Convention on the Rights of the Child;<sup>262</sup> and the African Charter on the Rights and Welfare of the Child may also be relevant in particular cases.<sup>263</sup>

At the sub-regional level, the SADC Protocol on Gender and Development (SADC Gender Protocol)<sup>264</sup> provides for important rights for women in the region.

**Table 2: Ratification of key international and regional treaties**

Country	ICCPR	ICESCR	CEDAW	CAT	African Charter	African Women's Protocol
Angola	Jan 1992	Jan 1992	Sept 1986	N/A	Mar 1990	Aug 2007
Botswana	Sep 2000	N/A	Aug 1996	Sep 2000	Jul 1986	N/A
DRC	Nov 1976	Nov 1976	Oct 1986	Mar 1996	Jul 1987	June 2008
Lesotho	Sep 1992	Sep 1992	Aug 1995	Nov 2001	Feb 1992	Oct 2004
Malawi	Dec 1993	Dec 1993	Mar 1987	Jun 1996	Nov 1989	May 2005
Mozambique	Jul 1993	N/A	Apr 1997	Sep 1999	Feb 1989	Dec 2005
Namibia	Nov 1994	Nov 1994	Nov 1992	Nov 1994	Jul 1992	Aug 2004
Swaziland	Mar 2004	Mar 2004	Mar 2004	Mar 2004	Sep 1995	N/A
Zambia	Apr 1984	May 1984	June 1985	Nov 1986	Jan 1984	May 2006
Zimbabwe	May 1991	May 1991	May 1991	N/A	May 1986	April 2008

1979, 1249 U.N.T.S. 13 (entered into force Sept. 3, 1981) [hereinafter CEDAW].

<sup>259</sup>Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, opened for signature Dec. 10, 1984, 1465 U.N.T.S. 85 (entered into force June 26, 1987) [hereinafter CAT].

<sup>260</sup>African Charter on Human and Peoples' Rights, opened for signature June 27, 1981, 1520 U.N.T.S. 217 (entered into force Oct. 21, 1986) [hereinafter African Charter].

<sup>261</sup>Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, opened for signature Sept. 13, 2000, OAU Doc. CAB/LEG/66.6 (entered into force Nov. 25, 2005) [hereinafter African Women's Protocol].

<sup>262</sup>Convention on the Rights of the Child, opened for signature Nov. 20, 1989, 1577 U.N.T.S. 3 (entered into force Sept. 2, 1990).

<sup>263</sup>African Charter on the Rights and Welfare of the Child, opened for signature July 11, 1990, OAU Doc. CAB/LEG/24.9/49 (entered into force Nov. 29, 1999).

<sup>264</sup>Southern Africa Development Community Protocol on Gender and Development, Aug. 17, 2008 [hereinafter SADC Protocol on Gender and Development].

### **Why a rights-based approach to addressing cervical cancer?**

Cervical cancer is a disease of inequality and poverty.<sup>265</sup> Mortality and incidence of cervical cancer tends to parallel the socio-economic environment across the globe and within countries. In South Africa, black women, particularly in rural areas, are at heightened risk for cervical cancer.<sup>266</sup> One study asserts that between 60-75% of women who develop cervical cancer in sub-Saharan Africa are from rural areas.<sup>267</sup>

Given that cervical cancer more heavily affects marginalised women, a rights-based approach is critical as it focuses on society's most marginalised or vulnerable.<sup>268</sup> Moreover, the rights-based approach highlights the notion that individuals are entitled to services, such as access to the prevention and treatment of cervical cancer, and that governments are required to provide them to its people.<sup>269</sup> A rights-based approach also ensures that people can hold government to account when such services are not adequately provided.<sup>270</sup>

The primary rights that require government to provide accessible, affordable and comprehensive cervical cancer services include the following:

#### **• Right to life**

Governments failing to provide access to preventative and curative care for cervical cancer impugn the right to life of affected women. The right to life is provided for under article 6(1) of the ICCPR; article 4 of the African Charter; and article 4 of the African Women's Protocol.

#### **• Right to the highest attainable standard of health**

The most obvious right affected by the inadequate provision of cervical cancer services is the right to health. The right to health has been part of international human rights since the adoption of the Universal Declaration of Human Rights (UDHR) in 1948. The ICESCR is the first binding instrument that recognises the right to health. The right to health is also recognised in article 12 of the CEDAW; article 16 of the African Charter; and article 14 of the African Women's Protocol. The SADC Gender Protocol also guarantees women's reproductive health rights.<sup>271</sup>

The right to health is inextricably linked to the realisation of other fundamental constitutional rights, including the right to life; non-discrimination; dignity; equality; and liberty.<sup>272</sup> The African Commission confirmed this, holding that the "[e]njoyment of

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<sup>265</sup>Kevin Outterson, *Will HPV Vaccines Prevent Cervical Cancers Among Poor Women of Color: Global Health Policy at the Intersection of Human Rights and Intellectual Property Law*, 35 AM. J. L. & MED. 247 (2009); Anorlu *supra* note 18, at 42–43.

<sup>266</sup>Moodley, *supra* note 14, at 11.

<sup>267</sup>Anorlu, *supra* note 18, at 41.

<sup>268</sup>Ebenezer Durojaye et al., *A Human Rights Response to Cervical Cancer in Africa*, 15 INT'L J. HUM. RTS. 416, 419 (2011).

<sup>269</sup>*Id.*

<sup>270</sup>*Id.*

<sup>271</sup>SADC Protocol on Gender and Development, *supra* note 264, at art. 26(b).

<sup>272</sup>Comm. on Economic, Social and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, para. 3, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000) [hereinafter ESCOR General Comment No. 14], available at <http://www.unhcr.ch/tbs/doc.nsf/%28symbol%29/E.C.12.2000.4.En>.

the human right to health as it is widely known is vital to all aspects of a person's life and well-being, and is crucial to the realisation of all the other fundamental human rights and freedoms".<sup>273</sup>

• **Rights to equality and freedom from all forms of discrimination**

Cervical cancer is a disease that only affects women. Furthermore, it disproportionately affects women living with HIV and women in rural areas. Failure to provide services that could save women's lives and the failure to address the needs of specific vulnerable populations violates their rights to equality and freedom from discrimination.<sup>274</sup>

The rights to equality and non-discrimination are recognised under articles 2(1), 3 and 26 of the ICCPR; articles 2(2) and 3 of the ICESCR; articles 1, 12(1) and 14(2) of the CEDAW; articles 2, 3, 18(3), and 19 of the African Charter; and article 2(1) of the African Women's Protocol.

• **Rights to dignity and freedom from cruel, inhuman, and degrading treatment**

Failure by southern African governments to plan and provide adequately for cervical cancer prevention and treatment services often results in the needless suffering of women from severe and prolonged physical pain. It can also result in the mental and emotional suffering of the patient and her family. Article 7 of the ICCPR; article 16 of CAT; article 5 of African Charter; and article 4 of African Women's Protocol all protect against cruel, inhuman or degrading treatment. Article 5 of the African Charter and article 3(1) of the African Women's Protocol provide for the right to dignity.

• **Right to information**

Access to information is closely linked to the attainment of other human rights. Without information regarding cervical cancer, women would be less likely to access life-saving services, even when they are available. In addition, without adequate, accurate information women will not be able to make informed decisions regarding treatment. Article 19(2) of the ICCPR and article 9 of the African Charter provide for the right to information.

• **Rights to liberty and security of the person**

The rights to liberty and security of the person – often considered part of the right to be free from cruel, inhuman and degrading treatment – give individuals control over their bodies and enable them to make autonomous decisions, which is critical in a medical context. The right to security and liberty is guaranteed under article 9 of the ICCPR, article 6 of the African Charter and article 4 of the African Women's Protocol.

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<sup>273</sup>*Purohit & Moore v. The Gambia, Afr. Comm'n on Hum. & Peoples' Rts.*, Communication No. 241/01, para. 80 (2001).

<sup>274</sup>CENTRE FOR REPRODUCTIVE RIGHTS, BACKGROUND PAPER TO SUPPORT THE DEVELOPMENT OF A GENERAL COMMENT ON THE RIGHT TO SEXUAL AND REPRODUCTIVE HEALTH BY THE COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS (CESCR COMMITTEE): INTERNATIONAL STANDARDS ON WOMEN'S SEXUAL AND REPRODUCTIVE RIGHTS AND GAPS IN THE INTERNATIONAL LEGAL FRAMEWORK 4 (2010) [hereinafter CRR BACKGROUND PAPER], available at [http://www2.ohchr.org/english/bodies/cescr/docs/discussion/CRR\\_DGD15112010.pdf](http://www2.ohchr.org/english/bodies/cescr/docs/discussion/CRR_DGD15112010.pdf).

## 4.1 Cervical cancer-related policies and guidelines

Under applicable international and regional law, countries are obligated to issue and implement a comprehensive policy on cervical cancer.

### **Duty to issue and implement a comprehensive policy on cervical cancer**

Southern African governments must develop and implement a comprehensive policy on cervical cancer. Article 12 of the ICESCR provides for the right to health. The Committee on Economic, Social and Cultural Rights (CESCR), tasked with interpreting the scope of the rights enshrined under the ICESCR, notes that the right to health requires countries to adopt “appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realisation of the right to health”.<sup>275</sup> It also requires state parties “to give sufficient recognition to the right to health in the national political and legal systems, preferably by way of legislative implementation, and to adopt a national health policy with a detailed plan for realising the right to health”.<sup>276</sup>

The requirement that governments issue policies to fully realise the right to health is particularly important when addressing the health needs of women, given the historic and continued discrimination against women. The CESCR emphasises that in order to eliminate discrimination against women, there is a need to develop and implement a comprehensive national strategy for promoting women’s right to health. The strategy should include:

interventions aimed at the prevention and treatment of diseases affecting women, as well as policies to provide access to a full range of high quality and affordable health care, including sexual and reproductive services... the removal of all barriers interfering with access to health services, education and information, including in the area of sexual and reproductive health.<sup>277</sup>

This is reinforced under the SADC Gender Protocol, which calls upon all member states to develop and implement policies and programmes to address the mental, sexual, and reproductive needs of women and men and to take into account the unequal status of women when developing such programmes.<sup>278</sup>

In southern Africa, where thousands of women die each year from cervical cancer, an official cervical cancer policy outlining programme priorities and providing concrete steps for implementation is critical to ensure adherence to international and regional legal obligations and in ending needless loss of life.

## 4.2 Cervical cancer-related prevention services

### **4.2.1 Availability of and access to information on cervical cancer**

Women in southern Africa have a right to comprehensive information about cervical cancer. This right is rooted in the rights to health; information; liberty and security of

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<sup>275</sup>ESCOR General Comment No. 14, *supra* note 272, at para. 33.

<sup>276</sup>*Id.* at para. 36.

<sup>277</sup>*Id.* at para. 21.

<sup>278</sup>SADC Protocol on Gender and Development, *supra* note 264, at art. 27.

the person; freedom from cruel, inhuman and degrading treatment; dignity; and non-discrimination. These rights require that countries do the following:

1. Provide comprehensive health information;
2. Provide accurate information;
3. Ensure informed consent for health services;
4. Provide a safe and supportive environment for adolescents to enjoy their sexual and reproductive rights;
5. Ensure equal access to health information; and
6. Ensure health workers are adequately trained.

### **Duty to provide comprehensive health information**

Southern African governments have a duty to provide the public with comprehensive information about cervical cancer. One of the core aspects of the right to health under article 12(1) of the ICESCR is the duty of governments to ensure the provision of health information, including methods of preventing and controlling particular illnesses.<sup>279</sup> According to the CESCR, the right to health includes “access to health-related education and information, including on sexual and reproductive health”.<sup>280</sup> Health-related information and education should include information on the availability of services and be available in local languages.<sup>281</sup>

When assessing country compliance with the rights enshrined in the ICESCR, the CESCR has expressed its concern about access to health information, particularly in the context of sexual and reproductive health. For example, in the context of HIV, the CESCR has called upon the Russian Federation to “ensure that all persons know about the disease and how to protect themselves, including through sex education in schools”.<sup>282</sup> The CESCR has also raised concern over the lack of sexual and reproductive health information in the area of maternal mortality, abortion and adolescent pregnancy.<sup>283</sup>

The United Nations Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical Mental Health (Special Rapporteur on the Right to Health) confirmed that “access to health related information and education is a crucial aspect of the right to health” and that “individuals are entitled to a full range of health information that bears upon them and their communities... includ[ing] information on preventive and health-promoting behaviour, as well as how to access health services”.<sup>284</sup> He also noted that the government of Uganda should adopt “public

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<sup>279</sup>ESCOR General Comment No. 14, *supra* note 272, at para. 44.

<sup>280</sup>*Id.* at para. 11.

<sup>281</sup>*Id.* at paras. 36–37. **See also** Comm. on Economic, Social and Cultural Rights, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt — Mission to Uganda, 62d Sess., Jan. 19, 2006, paras. 33, 35 U.N. Doc. E/CN.4/2006/48/Add.2 (Jan. 19, 2006) [hereinafter ESCOR Uganda Report], available at <http://www2.ohchr.org/english/issues/health/right/visits.htm>.

<sup>282</sup>Comm. on Economic, Social and Cultural Rights, Concluding Observations: Russian Federation, para. 62, U.N. Doc. E/C.12/1/Add.94 (Dec. 12, 2003) available at <http://www.unhcr.ch/tbs/doc.nsf/%28Symbol%29/E.C.12.1.Add.94.En?Opendocument>.

<sup>283</sup>CRR Background Paper, *supra* note 274, at 7.

<sup>284</sup>ESCOR Uganda Report, *supra* note 181, at para. 33.

information campaigns targeting disadvantaged rural and urban communities, which should utilise the mass media, village health teams, health professionals, church and other faith networks, schools, trade unions, and any other useful body or organisation” so as to raise awareness on unknown diseases.<sup>285</sup> He has also recommended that important health information aimed at raising awareness should be available in local languages and particular effort should be made to dispel harmful misconceptions about diseases, particularly neglected and unknown diseases.<sup>286</sup>

The Committee on the Elimination of Discrimination against Women (CEDAW Committee) noted its concern that very few women in Bahrain accessed cervical cancer screening services and recommended that Bahrain “undertake systematic awareness-raising among women on the importance of regular medical examination to facilitate early detection of breast and cervical cancer”.<sup>287</sup>

At the regional level, article 14 of the African Women’s Protocol obligates countries to provide adequate, affordable and accessible health services, which includes providing “information, education and communication programmes to women”. Public education is a core aspect of the African Women’s Protocol, leading the African Commission to require countries to explain the measures of implementation they have undertaken with regard to public education when reporting on compliance with the African Women’s Protocol.<sup>288</sup>

The need for widely-available information on cervical cancer is reinforced by other international and regional declarations. The Beijing Platform for Action, adopted in September 1995, calls on governments to “inform women about the factors which increase the risks of developing cancers and infections of the reproductive tract, so that they can make informed decisions about their health”.<sup>289</sup>

At the sub-regional level, the Maputo Plan of Action for the Operationalisation of the Continental Policy Framework for Sexual and Reproductive Health Rights recommends that countries “provide appropriate information on the provision of integrated STI/HIV/AIDS and [sexual and reproductive health] services”.<sup>290</sup>

Providing comprehensive information on cervical cancer is necessary to ensure women have access to cervical cancer services and can exercise their fundamental rights.

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<sup>285</sup>ESCOR Uganda Report, *supra* note 181, at para. 35.

<sup>286</sup>*Id.*

<sup>287</sup>CEDAW Comm., Concluding Observations: Bahrain, para. 37, U.N. Doc. CEDAW/C/BHR/CO/2 (Nov. 14, 2008), available at <http://www2.ohchr.org/english/bodies/cedaw/cedaws42.htm>.

<sup>288</sup>AFRICAN COMMISSION ON HUMAN & PEOPLES’ RIGHTS, GUIDELINES FOR STATE REPORTING UNDER THE PROTOCOL TO THE AFRICAN CHARTER ON HUMAN AND PEOPLES’ RIGHTS ON THE RIGHTS OF WOMEN IN AFRICA, iii(e), iv(4) (2010).

<sup>289</sup>FOURTH WORLD CONFERENCE ON WOMEN: ACTION FOR EQUALITY, DEVELOPMENT AND PEACE, BEIJING PLATFORM FOR ACTION para. 109(e) (1995) (U.N.).

<sup>290</sup>African Union Commission, Plan of Action on Sexual and Reproductive Health and Rights (Maputo Plan of Action), 9, A.U. Doc. Sp/MIN/CAMH/5(I) (Sept. 18–22, 2006), available at [http://www.unfpa.org/africa/newdocs/maputo\\_eng.pdf](http://www.unfpa.org/africa/newdocs/maputo_eng.pdf). This is a document promoting universal access to comprehensive sexual and reproductive health services in Africa.

**Duty to provide accurate information**

In addition to providing information and education about cervical cancer, southern African governments have an obligation to ensure that the information presented is accurate. This includes requirements that information not be withheld or intentionally misrepresented, particularly to propagate the specific religious or cultural beliefs of individual health workers.<sup>291</sup> In addressing barriers to accessing contraception in Poland, the Special Rapporteur on the Right to Health recommended that Poland adopt:

mandatory, age-appropriate, comprehensive, science and evidence-based, non-discriminatory and gender-sensitive sexuality education taught by appropriately trained personnel, including non-judgemental information and education on healthy relationships and family life, sex and relationships, and comprehensive sexual and reproductive health.<sup>292</sup>

The Inter-American Commission on Human Rights, tasked with monitoring compliance with the American Convention on Human Rights, held in a case involving public officials providing patients and their family with distorted information on reproductive health in an effort to dissuade them from accessing specific services, that such misinformation was a denial of the patient's right to health.<sup>293</sup> In the case, the patient requested an abortion. In response, the doctor inaccurately described the risks of the procedure to the patient's mother as including "sterility, perforation of the uterus, massive hemorrhage, Asherman's syndrome, and death". He also told the patient's mother that she would be responsible if her daughter were to die while accessing the abortion.<sup>294</sup> In light of the doctor's erroneous information, the mother chose not to proceed with the abortion.

Intentionally misrepresenting health information is not only a gross violation of an individual's right to health, but also a violation of her rights to security of the person and dignity as it denies the patient the information needed to make an informed decision regarding her health and body.<sup>295</sup>

**Duty to ensure informed consent for health services**

Providing complete, accurate and reliable information to patients regarding their health is a critical component of obtaining informed consent. Informed consent is a well-developed medical and legal concept. Informed consent must be obtained before any medical procedure is performed on a patient. With respect to cervical cancer, this would include obtaining informed consent prior to the following: giving a patient an HPV vaccine; screening; treatment for pre-cancerous lesions; treatment for invasive cervical cancer; and administering pain relief.

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<sup>291</sup>ESCOR General Comment No. 14, *supra* note 272, at para. 34.

<sup>292</sup>U.N. GAOR, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover — Mission to Poland, 14th Sess., May 5–11, 2009, para. 85(b), U.N. Doc. A/HRC/14/20/Add.3 (May 20, 2010).

<sup>293</sup>Inter-Am. Comm'n H.R., Access to Information on Reproductive Health from a Human Rights Perspective, Nov. 22, 2011, para. 6, Doc. OEA/Ser.L/V/II (2011) [hereinafter IACHR Reproductive Health Report].

<sup>294</sup>Inter-Am. Comm'n H.R., Friendly Settlement, *Paulina del Carmen Ramirez Jacinto (Mex.)*, Mar. 9, 2007, para. 13, Rep. No. 21/07, Petition 161/02, available at <http://www.cidh.oas.org/annualrep/2007/eng/Mexico161.02eng.htm>.

<sup>295</sup>ESCOR General Comment No. 14, *supra* note 272, at paras. 34, 50.



Informed consent requires:

1. providing the patient with current, accurate and complete information on the nature of the procedure, treatment options, and reasonable alternatives, including the potential benefits and risks of proposed procedures;
2. providing information in a language and manner which the patient understands and ensuring that the patient understands the information provided; and
3. ensuring that any consent provided is free and voluntary and that the patient is given adequate time to consider the information provided.<sup>296</sup>

Failure to obtain informed consent, including failing to provide a patient with the appropriate information needed to make an informed decision, violates the rights to dignity; freedom from cruel, inhuman and degrading treatment; liberty and security of the person; health; and privacy. The CEDAW Committee, tasked with determining the breadth and scope of the rights under the CEDAW, has noted that women “have the right to be fully informed, by properly trained personnel, of their options in agreeing to treatment or research, including likely benefits and potential adverse effects of proposed procedures and available alternatives”.<sup>297</sup> The CEDAW Committee further recommended that countries “ensure that all health services are consistent with the human rights of women, including the rights to autonomy, privacy, confidentiality, informed consent and choice”.<sup>298</sup>

The CEDAW Committee addressed the issue of informed consent in a case against Hungary. In the case, the petitioner had been subjected to a coerced sterilisation, during a surgical intervention. She had not received any information on the procedure in a manner which she could comprehend nor was she informed of the effects the procedure would have on her fertility.<sup>299</sup> The CEDAW Committee found that Hungary had violated her right to appropriate healthcare services as the information on the sterilisation was inadequate for informed consent.<sup>300</sup>

Similarly, the Human Rights Committee (HRC), monitoring compliance with the ICCPR, has indicated that obtaining informed consent in medical settings is a critical component of the ICCPR’s right to be free from cruel, inhuman or degrading treatment.<sup>301</sup> With respect to Peru’s forced sterilisations of indigenous women in rural areas, the HRC insisted that Peru “take the necessary measures to ensure that persons who undergo surgical contraception procedures are fully informed and give their consent freely”.<sup>302</sup> In some cases, failure to obtain the informed consent of patients would violate the rights to equality and freedom from discrimination. This is particularly true with respect to cervical cancer, an illness that affects women and often women who are most

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<sup>296</sup>IACHR Reproductive Health Report, *supra* note 293, at 13.

<sup>297</sup>CEDAW General Recommendation No. 24, *supra* note 53, at para. 20.

<sup>298</sup>*Id.* at para. 31(e).

<sup>299</sup>CEDAW Comm., *A.S. v. Hungary*, Comm. No. 4/2004, U.N. Doc. CEDAW/C/36/D/4/2004 (Aug. 29, 2006), available at [http://www.escri-net.org/usr\\_doc/CEDAW\\_Committee\\_Decision.pdf](http://www.escri-net.org/usr_doc/CEDAW_Committee_Decision.pdf).

<sup>300</sup>*Id.* at para. 11.2.

<sup>301</sup>Human Rights Comm., 44th session, 1992, General Comment No. 20, para. 2, available at [http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/6924291970754969c12563ed004c8ae5?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/6924291970754969c12563ed004c8ae5?Opendocument).

<sup>302</sup>Human Rights Comm., Concluding Observations: Peru, para. 21, U.N. Doc. CCPR/CO/70/PER, (Nov. 15, 2000), available at <http://www.unhcr.org/refworld/docid/3b39f0d96.html>.

marginalised, including women living with HIV and rural women. To ensure compliance with international and regional law obligations, countries must ensure that health workers and health policies are not discriminatory. Discriminatory policies, including policies that result in discriminatory impact, or result in entrenching existing scepticism of the healthcare workers and health facilities, make it less likely that those most in need will access the required services.

**Duty to provide a safe and supportive environment for adolescents to enjoy their sexual and reproductive health rights**

Southern African governments have a particular duty towards adolescents to provide them a safe and supportive environment such that they can participate in decisions affecting their health; acquire appropriate information; receive counselling; and negotiate the health-behaviour choices they make.

The Committee on the Rights of the Child has confirmed that countries have a duty to refrain from censoring, withholding, and intentionally misrepresenting health-related information, including information on sexual education.<sup>303</sup>

This is particularly important with respect to cervical cancer as the HPV vaccines are most effective when taken in adolescence. In addition, young women who are informed on the nature of cervical cancer will be able to better protect themselves against invasive cancer through regular screenings from an early age.

**Duty to ensure equal access to health information**

The right to equality between men and women is a fundamental right under international and regional law and is included in the ICCPR, ICESCR, CEDAW, the African Charter, and the African Women's Protocol.<sup>304</sup>

The obligation of southern African governments to ensure equality between men and women, includes equal "access to health-care services and information and education".<sup>305</sup> The CEDAW Committee, highlighting their concern that many countries fail to provide access to sexual health information emphasised that countries "should ensure, without prejudice or discrimination, the right to sexual health information, education and services for all women and girls".<sup>306</sup>

**Duty to ensure that health workers are adequately trained**

In order to ensure patients' rights are not violated, southern African governments must ensure that healthcare providers receive adequate training and access to medically accurate health information. Training of health workers is a component of realising the right to health. The CESCR has noted that countries have an obligation to ensure that health workers have access to appropriate information for prevention and treatment of

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<sup>303</sup>Comm. on the Rights of the Child, General Comment 3: HIV/AIDS and the Rights of the Child, para. 16, U.N. Doc. CRC/GC/2003/3 (Mar. 17, 2003), available at <http://www2.ohchr.org/english/bodies/crc/comments.htm>.

<sup>304</sup>ICCPR, *supra* note 256, at arts. 2(1) and 26; ICESCR, *supra* note 257, at arts. 2(2) and 3; CEDAW, *supra* note 258, at arts.1, 12(1) and 14(2); African Charter, *supra* note 260, at arts. 2, 3, 18(3), and 19; African Women's Protocol, *supra* note 261, at art. 2(1).

<sup>305</sup>CEDAW General Recommendation No. 24, *supra* note 53, at para. 13.

<sup>306</sup>*Id.* at para. 18.

diseases.<sup>307</sup> It further stated that health services must be “scientifically and medically appropriate and of good quality,” and that quality services require, among other things, “skilled medical personnel”.<sup>308</sup>

#### **4.2.2 Vaccines**

Women in southern Africa have a right to cervical cancer prevention services, including HPV vaccines as part of the right to health.

Under international and regional law obligations, countries are obligated to ensure access to medicines.

#### **Duty to ensure access to medicines**

Southern African governments have a duty to provide access to medicine as a fundamental element in achieving the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.<sup>309</sup> Though HPV vaccines are not currently classified as essential drugs by the WHO, the CECSR has confirmed that the obligation to provide immunisation against the major infectious diseases occurring in the community should be a priority.<sup>310</sup> In southern Africa, where cervical cancer is often the leading cause of cancer death among women, obtaining a vaccine which could drastically reduce deaths from cervical cancer should be a priority.

Governments have an obligation to take appropriate measures to the extent possible to ensure that women realise their rights to healthcare.<sup>311</sup> Southern African countries, individually and as a regional block, should investigate all legal strategies available to expand access to the HPV vaccines for women in their countries. This should include advocacy to have HPV vaccines included on the international essential medicines list in order to utilise flexibilities under the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS).<sup>312</sup> In 2001, the World Trade Organisation issued the Doha Declaration on the TRIPS Agreement and Public Health (Doha Declaration), which confirmed flexibility under TRIPS for countries in providing essential medicines, as defined by the WHO.<sup>313</sup> The Doha Declaration provides:

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<sup>307</sup>ESCOR General Comment No. 14, *supra* note 272, at para. 12.

<sup>308</sup>*Id.*

<sup>309</sup>U.N. Human Rights Council, Access to Medicine in the Context of the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, at 2, U.N. Doc. A/HRC/RES/12/24 (Oct. 12, 2009), available at <http://www2.ohchr.org/english/bodies/hrcouncil/12session/resdec.htm>.

<sup>310</sup>ESCOR General Comment No. 14, *supra* note 272, at para. 44(b).

<sup>311</sup>CEDAW General Recommendation No. 24, *supra* note 53, at para. 17.

<sup>312</sup>TRIPS is the legal instrument driving international patent protection. It was signed in Uruguay in 1994 under the auspices of the World Trade Organisation (WTO). It sets minimum standards in the international rules governing patents, including on medicines. Under TRIPS, countries that are members of the WTO (today, more than 150 countries and including most southern African States) agree to certain common standards in the way they enact and implement their patent laws. These standards include, amongst others, that patents be granted for a minimum of 20 years; that patents may be given both for products and processes; and that pharmaceutical test data be protected against “unfair commercial use”. The agreement allows for certain flexibilities to patent laws to allow state parties to realise the right to access to medicines. Agreement Establishing the World Trade Organization, Annex 1C, Apr. 15, 1994, 1867 U.N.T.S. 154, 33 I.L.M. 1144.

<sup>313</sup>The WHO defines essential medicines as those that satisfy the priority health care needs of the population,

Accordingly, while reiterating our commitment to the TRIPS Agreement, we affirm that the Agreement can and should be interpreted and implemented in a manner supportive of WTO members' right to protect public health and, in particular, to promote access to medicines for all.<sup>314</sup>

This allows for countries to explore possible options for acquiring cheaper versions of the HPV vaccine for use in public health facilities and should be explored by countries in the region.

#### **4.2.3 Screening**

Women in southern Africa have a right to cervical cancer prevention services, including cervical cancer screening services. This right is rooted in protection of the right to health and the rights to non-discrimination and equality. These rights require government to provide preventative health services; ensure equitable distribution of health services; and ensure health services are gender-sensitive.

#### **Duty to provide preventative health services**

Southern African governments have an obligation to provide screening services as an integral part of the right to health. The CESCR notes that the right to health facilities, goods, and services includes "equal and timely access to basic preventive, curative, rehabilitative health services and health education; [and] regular screening programmes... preferably at community level".<sup>315</sup>

The CEDAW Committee has regularly expressed its concern that countries do not adequately provide preventative services for cervical cancer.<sup>316</sup> In response to concerns that cervical cancer was a leading cause of death for women in Nicaragua, the CEDAW Committee recommended that Nicaragua "implement[... ] programmes to prevent cervical and breast cancer".<sup>317</sup>

When countries do take measures to ensure the availability of preventative health services, the CEDAW Committee notes such actions with approval. When assessing Hungary's compliance with CEDAW, the CEDAW Committee applauded Hungary's decision to implement cervical cancer screening programmes.<sup>318</sup>

#### **Duty to ensure equitable distribution of health services**

States have an obligation to ensure equitable distribution of health facilities, goods,

available at [http://www.who.int/medicines/services/essmedicines\\_def/en/](http://www.who.int/medicines/services/essmedicines_def/en/).

<sup>314</sup>World Trade Organization, Declaration on the TRIPS Agreement and Public Health, para. 4, W.T.O. Doc. WT/MIN(01)/DEC/2 (Nov. 20, 2001), available at [http://www.wto.org/english/thewto\\_e/minist\\_e/min01\\_e/mindecl\\_trips\\_e.htm](http://www.wto.org/english/thewto_e/minist_e/min01_e/mindecl_trips_e.htm).

<sup>315</sup>ESCOR General Comment No. 14, *supra* note 272, at para. 17.

<sup>316</sup>See, e.g. CEDAW Comm., Concluding Observations: Ecuador, paras. 40-41, U.N. Doc. CEDAW/C/ECU/CO/7 Nov. 7, 2008, available at [http://www.iwraw-ap.org/committee/pdf/42\\_concluding\\_observations/ecuador.pdf](http://www.iwraw-ap.org/committee/pdf/42_concluding_observations/ecuador.pdf).

<sup>317</sup>Report of the CEDAW Comm., at Ch. V, para. 301, U.N. Doc. A/56/38 (Part I) (Nicaragua) Jan. 15-Feb. 2, 2001, July 2-20, 2001, available at <http://uhri.ohchr.org/Document/File/8c8f3639-882a-4128-8f03-45abe239e8a7/a384543b-d6a7-446c-819f-af52633e3c06>.

<sup>318</sup>CEDAW Comm., Concluding comments: Hungary, para. 6, U.N. Doc. CEDAW/C/HUN/CO/6 10 Aug 2007, available at <http://uhri.ohchr.org/Document/File/2b755dc3-a0ff-4b27-9351-3a3fc1d36916/676842ff-0be3-44d3-bdd7-e48244cd79a6>.

and services,<sup>319</sup> including the provision of a sufficient number of hospitals, clinics and other health-related facilities with due regard to equitable distribution throughout the country.<sup>320</sup> The CESCR has on occasion called upon states to ensure “equitable access to health services in all regions of the country”.<sup>321</sup>

Equitable access requires that there be both physical or geographic accessibility and economic accessibility, primarily meaning affordability.<sup>322</sup> The dearth of health services outside of main cities severely impacts on people’s ability to access healthcare in southern Africa. With respect to cervical cancer, in both Namibia and Zambia, screening services are primarily available in the capital cities, creating significant obstacles for women in rural areas to access the services.

In addition, the lack of services available in public health facilities raises economic obstacles, as poor women will be unable to access those services only available in the private sector. The South African Constitutional Court addressed this concern in the *Minister of Health and Others v. Treatment Action Campaign and Others*,<sup>323</sup> when it considered, among other issues, the accessibility of nevirapine – a drug used to prevent mother-to-child transmission of HIV. At the time, South Africa only provided nevirapine at two research and training sites per province. The drug was also available in the private health system. The Court noted its concern that the lack of accessibility would primarily affect the poor:

In dealing with these questions it must be kept in mind that this case concerns particularly those who cannot afford to pay for medical services. To the extent that government limits the supply of nevirapine to its research sites, it is the poor outside the catchment areas of these sites who will suffer. There is a difference in the positions of those who can afford to pay for services and those who cannot. State policy must take account of these differences.<sup>324</sup>

Southern African countries have an obligation to take reasonable measures to ensure equitable access to screening services by rolling out screening services to sites outside of capital cities and urban centres and ensuring critical services are available within the public health system.

### **Duty to ensure health services are gender-sensitive**

Healthcare services must be gender-sensitive and take into account the peculiar needs of women. CEDAW expressly addresses equality in healthcare and requires countries to “take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services”.<sup>325</sup> The CEDAW Committee has noted that measures taken to eliminate

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<sup>319</sup>ESCOR General Comment No. 14, *supra* note 272, at para. 43(e).

<sup>320</sup>*Id.* at para. 36.

<sup>321</sup>ESCOR, Concluding Observations: Russian Federation, para. 59, U.N. Doc. E/C.12/1/Add.94 Dec. 12, 2003, available at [http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/E.C.12.1.Add.94.En?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/E.C.12.1.Add.94.En?Opendocument).

<sup>322</sup>ESCOR General Comment No. 14, *supra* note 272, at para.12(b).

<sup>323</sup>*Minister of Health and Others v Treatment Action Campaign and Others*, 2002 (5) SA 721 (CC) (S. Afr.).

<sup>324</sup>*Id.* at para. 70.

<sup>325</sup>CEDAW, *supra* note 258, at art. 12(1).

discrimination against women with regard to the right to health will be deemed to be inadequate if such measures fail to prevent, detect and treat illnesses which specifically affect women.<sup>326</sup> The CEDAW Committee in considering article 12, which guarantees freedom from discrimination, has on several occasions noted its concern with the limited number of women who undergo cervical cancer screenings and recommended that countries strengthen their preventative screening services.<sup>327</sup>

Cervical cancer is fully preventable and curable, at low cost and at low risk, as long as screening for low grade pre-cancerous lesions is available and accessible for all women. Under international and regional law, countries are obligated to ensure women have access to screening services.

### 4.3 Treatment

Women in southern Africa have a right to cervical cancer treatment. This right is entrenched in the rights to life and health. Countries have a duty under international and regional law to provide life-saving treatment.

#### **Duty to provide life-saving treatment**

Southern African governments have an obligation to prevent the loss of lives due to cervical cancer, which if untreated will lead to death. The HRC notes that the right to life should not be interpreted too narrowly and that the protection of this right requires that states adopt positive measures to avoid unnecessary loss of life.<sup>328</sup>

The HRC has made it clear that the failure to provide adequate healthcare implicates the right to life. In 2004, the HRC, in considering Uganda's compliance with its obligations under the ICCPR, found that the right to life was implicated with respect to "access to medical services, including antiretroviral treatment, to persons infected with HIV".<sup>329</sup> Similarly, in the case of cervical cancer, lack of available treatment to address invasive cancer and in some cases pre-cancerous lesions will result in a loss of life, resulting in a violation of the right to life.

### 4.4 Palliative care services

Women in southern Africa have a right to palliative care services. This right is embedded in the right to health; the right to freedom from cruel, inhuman and degrading treatment; and the right to dignity.

Under international and regional law, countries are obligated to prevent physical pain and mental suffering.

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<sup>326</sup>CEDAW General Recommendation No. 24, *supra* note 53, at para. 11.

<sup>327</sup>CEDAW Comm., Concluding observations: Bahrain, para. 36, U.N. Doc. CEDAW/C/BHR/CO/2 Oct. 20-Nov. 7, 2008, available at [http://www.iwraw-ap.org/committee/pdf/42\\_concluding\\_observations/bahrain.pdf](http://www.iwraw-ap.org/committee/pdf/42_concluding_observations/bahrain.pdf).

<sup>328</sup>Human Rights Comm., General Comment No. 6: The right to life (art. 6), para. 5, Apr. 30, 1982, available at [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/84ab9690ccd81fc7c12563ed0046fae3?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/84ab9690ccd81fc7c12563ed0046fae3?Opendocument).

<sup>329</sup>Concluding Observations of the Human Rights Committee: Uganda, para. 14, U.N. Doc. CCPR/CO/80/UGA May 4, 2004, available at [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/CCPR.CO.80.UGA.En?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/CCPR.CO.80.UGA.En?Opendocument).

### **Duty to prevent physical suffering**

Southern African governments have a duty to avoid preventable suffering of patients. Due to the limited number of women accessing screening services, many cervical cancer cases are only diagnosed when they are advanced and incurable.<sup>330</sup> Advanced cervical cancer can result in immense physical anguish. Adequate pain control is important to prevent suffering of women with advanced cervical cancer.<sup>331</sup> According to the WHO, “most, if not all, pain due to cancer could be relieved if we implemented existing medical knowledge and treatments”.<sup>332</sup>

Failure by states to make available comprehensive services, which include effective pain relief for those diagnosed with advanced cervical cancer, can violate the prohibition against cruel, inhuman and degrading treatment and the right to dignity.

The ICCPR, African Charter, African Women’s Protocol and the CAT all protect against cruel, inhuman or degrading treatment.<sup>333</sup> The right to be free from torture and other cruel, inhuman, or degrading treatment cannot be violated under any circumstance, and governments must take immediate action to address it. This right requires countries to proactively ensure that people are protected from health-related pain and suffering.<sup>334</sup> The UN Special Rapporteurs on Torture and Other Cruel Inhumane and Degrading Treatment and on the Right to the Highest Attainable Standard of Health have stated that the failure by states to ensure access to controlled medications for pain and suffering threatens fundamental rights to health and protection against cruel, inhuman and degrading treatment.<sup>335</sup>

The African Charter and the African Women’s Protocol both provide for the right to dignity. In cases where women die in immense physical pain and no pain relief medication is available, their dignity is substantially impaired. The CESCR emphasised the importance of dignity at the end stages of life, noting the need for “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity”.<sup>336</sup>

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<sup>330</sup>Moodley, *supra* note 14, at 11.

<sup>331</sup>Cain, *Women’s options*, *supra* note 65, at 143.

<sup>332</sup>WHO, ACHIEVING BALANCE IN OPIOID CONTROL POLICY 1 (2000), available at <http://www.medsch.wisc.edu/painpolicy/publicat/00whoabi/00whoabi.pdf>.

<sup>333</sup> ICCPR, *supra* note 256, at art. 7; African Women’s Protocol, *supra* note 261, at art. 4(1); CAT, *supra* note 259, at art. 16.

<sup>334</sup>HRW REPORT ON PAIN TREATMENT, *supra* note 248, at 16.

<sup>335</sup>U.N. Office of the High Commissioner for Hum. Rts., Letter dated Dec. 10, 2008 from the Special Rapporteurs on the prevention of torture and cruel, inhuman, or degrading treatment or punishment and on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, addressed to the Chairperson of the 52d Sess. of the Commission on Narcotic Drugs, available at [http://www.hrw.org/sites/default/files/related\\_material/12.10.2008%20Letter%20to%20CND%20fromSpecial%20Rapporteurs.pdf](http://www.hrw.org/sites/default/files/related_material/12.10.2008%20Letter%20to%20CND%20fromSpecial%20Rapporteurs.pdf). **See also** Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, para. 72, U.N. Doc. A/HRC/10/44 Jan. 14, 2009, available at <http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.44AEV.pdf> (“Similarly, the Special Rapporteur is of the opinion that the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment”).

<sup>336</sup>ESCOR General Comment No. 14, *supra* note 272, at para. 25.

**Duty to prevent mental suffering**

In addition, southern African governments also have the duty to prevent unnecessary mental suffering. Late symptoms of cervical cancer such as vaginal discharge, sores and bleeding, urinary or bowel fistulas, diarrhea and pelvic pain are not only physically painful, but have a significant psychosocial impact on the patient and her family.<sup>337</sup> These late-stage disease symptoms, which can leave the patient and her family in isolation, could be addressed with adequate availability of and access to palliative care services.<sup>338</sup>

The failure to provide access to services, which can alleviate mental suffering violates the right to dignity and the right to be free from cruel, inhuman and degrading treatment. The African Commission in interpreting the prohibition of torture, cruel, inhuman and degrading treatment or punishment held that it ought “to be interpreted so as to extend to the widest possible protection against abuses, whether physical or mental”.<sup>339</sup> The African Commission has also noted that “exposing victims to personal sufferings and indignity violates the right to human dignity,”<sup>340</sup> further noting that “personal suffering and indignity can take many forms”.<sup>341</sup>

The prohibition of cruel, inhuman and degrading treatment is similarly interpreted under international law. The HRC has stated that the aim of article 7 of the ICCPR, prohibiting cruel, inhuman and degrading treatment, is to “protect both the dignity and the physical and mental integrity of the individual”.<sup>342</sup> In *K.L. v Peru*,<sup>343</sup> the HRC found that Peru’s denial of a therapeutic abortion to a patient, which caused her depression and emotional distress, violated article 7.

## 4.5 Conclusion

Under international and regional law, countries in southern Africa are obligated to provide access to cervical cancer services and make them available to all women. The failure to provide women with access to cervical cancer services violates their fundamental rights and will continue to result in the loss of thousands of lives each year.

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<sup>337</sup>Cain, *Women’s options*, *supra* note 65, at 141.

<sup>338</sup>*Id.*

<sup>339</sup>*Huri-Laws v Nigeria*, Afr. Comm. 225/98 para. 40 (2000).

<sup>340</sup>*Sudan Hum. Rts. Org. & Centre on Housing Rts. & Evictions (COHRE) v Sudan*, Afr. Comm. 279/03-296/05 para. 158 (2009).

<sup>341</sup>*Id.*

<sup>342</sup>Human Rights Comm., General Comment No. 20: Article 7 (Prohibition of Torture, or Other Cruel, Inhuman or Degrading Treatment or Punishment), para. 2, Mar. 10, 1992, available at [http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/6924291970754969c12563ed004c8ae5?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/6924291970754969c12563ed004c8ae5?Opendocument).

<sup>343</sup>Human Rights Comm., *K.L. v Peru*, Comm. No. 1153/2003, U.N. Doc. CCPR/C/85/D/1153/2003 Nov. 22, 2005, available at <http://reproductiverights.org/sites/crr.civicactions.net/files/documents/KL%20HRC%20final%20decision.pdf>.



## 5. Recommendations

Interventions for cervical cancer control can be adopted for virtually every resource and demographic situation.<sup>344</sup> Failure by southern African countries to implement cervical cancer control and management programmes results in women and their families suffering needlessly and denies women their human rights. Southern African countries, as signatories to numerous international and regional human rights treaties, have an obligation to ensure that they protect women's sexual and reproductive health rights. Many of the core rights obligating states to protect women's sexual and reproductive health rights are also enshrined in each country's national constitution. In Namibia, the constitution protects the right to life;<sup>345</sup> the right to human dignity,<sup>346</sup> the right to be free from cruel, inhuman and degrading treatment;<sup>347</sup> and the rights to equality and freedom from discrimination.<sup>348</sup> The Zambian constitution guarantees among others the right to life,<sup>349</sup> the right to freedom from inhuman treatment;<sup>350</sup> and the right to non-discrimination.<sup>351</sup>

The failure to provide access to cervical cancer services results in the violation of fundamental rights and in the loss of countless lives. There is a serious and urgent need to improve services for cervical cancer in the southern Africa region. This report recommends that countries take the following steps to effectively address cervical cancer.

### **Recommendations for all countries in southern Africa**

- Develop a comprehensive national policy on cervical cancer management. The policy must, at minimum, address the following:
  - primary prevention, including determining how awareness will be raised and information disseminated, and providing guidance on HPV vaccines;
  - secondary prevention or screening, including providing the age at which screening should start and the frequency of screening;
  - diagnosis;

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<sup>344</sup>Cain, *Women's options*, *supra* note 65, at 141.

<sup>345</sup>CONST. OF NAMIBIA, art. 6.

<sup>346</sup>*Id.* at art. 8(1).

<sup>347</sup>*Id.* at art. 8(2)(b).

<sup>348</sup>*Id.* at art. 10.

<sup>349</sup>CONST. OF ZAMBIA of 1991 (as amended by Act No. 18 of 1996), art. 12.

<sup>350</sup>*Id.* at art. 15.

<sup>351</sup>*Id.* at art. 23.

## 5. RECOMMENDATIONS

- treatment protocols for pre-cancerous lesions and invasive cervical cancer;
  - provision of palliative care; and
  - the needs of particularly vulnerable groups, such as women living with HIV.
- Widely disseminate information on cervical cancer, including risks, prevention options and treatment methods. Ensure information is available, in both print and orally, and in local languages.
  - Provide free cervical cancer screening services throughout the country in the public health system.
  - Integrate cervical cancer screening within existing sexual and reproductive health services.
  - Explore avenues through which countries can acquire necessary medications, including the HPV vaccine and morphine for wide use in the public health system.
  - Allocate adequate human, financial and other resources for the management of cervical cancer.
  - Establish effective cancer registries at regional and national levels to enable adequate assessment of the impact of cervical cancer screening programmes.
  - Implement effective means of monitoring and evaluating cervical cancer programmes.

### **Particular recommendations for the Government of Namibia in addition to those outlined above**

- Implement alternative screening methods, such as the visual inspection method, and the see-and-treat approach in public health facilities.
- 
- Train all healthcare workers on comprehensive cervical cancer management. Healthcare workers should specifically be educated on the risks, prevention methods and treatment options for cervical cancer; principles of informed consent; preventing entrenchment of HIV-related stigma and discrimination; and the rights of adolescents to sexual and reproductive health.

### **Particular recommendations for the Government of Zambia in addition to those outlined above**

- Train healthcare workers to undertake screening and ensure that the appropriate equipment is available at the clinic level.
- Expand laboratory services to ensure the speedy return of pathological results.

# Annexures

## Annexure one - Questionnaire on policies and programmes on cervical cancer services in southern Africa

### 1. Respondent Information

Your country:

Respondent's name (optional):

Name of organisation/department:

Your organisation's phone number and fax:

Your organisation's email address and website:

Which best describes the sector that you represent. Please tick the appropriate box.

- 1) The Ministry/Department of Health
- 2) A National AIDS Coordinating Body
- 3) A Network/Association of People Living with HIV
- 4) A United Nations Agency
- 5) An International Non-Governmental Organisation
- 6) A Regional Non-Governmental Organisation
- 7) A National Non- Governmental Organisation
- 8) A Community-Based Organisation
- 9) Other (please specify) \_\_\_\_\_.

**Which of the following issue(s) does your organisation work on?  
Please tick all that apply.**

Human rights issues in general

Access to healthcare and other health issues in general

Women's rights and development issues in general

Sexual and reproductive health rights

Rights of people living with HIV

Rights of women living with HIV

Other (Please specify) \_\_\_\_\_

Have you previously engaged in or do you currently do any work related to cervical cancer? If yes, please describe this work below.



## 2. Relevant policies, plans, strategies or guidelines

Please answer YES, NO or DON'T KNOW in each column.

Policy	Is this policy available in your country?	Does it say anything about cervical cancer?
1. National Cervical Cancer Management Policy/Plan/Strategy/Guideline		
2. National (General) Cancer Management Policy/Plan/Strategy/Guideline		
3. National Health Policy/Plan/Strategy/Guideline		
4. National Gender Policy/Plan/Strategy/Guideline		
5. National AIDS Policy/Plan/Strategy/Guideline		
6. National Sexual and Reproductive Health Policy/Plan/Strategy/Guideline		
7. National Sexually Transmitted Infections Management Policy/Plan/Strategy/Guideline		
8. National Palliative Care Policy/Plan/Strategy/Guideline		
9. National Home-Based Care Policy		

**3. Access to cervical cancer programmes**

- a. Does your country have specific cervical cancer management guidelines for women living with HIV? If yes, please provide the name of the document.
- b. Are you aware of any other guideline, policy, plan or strategy in your country other than those already mentioned in the table above that addresses issues related to cervical cancer? If yes, please provide the name of the document(s).
- c. Are you are aware of cervical cancer programme(s) being implemented in your country or services being offered particularly to women of lower economic status? Please provide as much information as you can about the programme. For example, who runs the programme; is it implemented through government health facilities or private sector facilities, including non-governmental organisations; are the services accessible in all areas in the country or are they in a specific area or district of the country?
- d. In your opinion, would you say sexually active women of reproductive age are generally knowledgeable about cervical cancer in your country? Please explain your answer.
- e. In your opinion, would you say women living with HIV are generally knowledgeable about cervical cancer, its intersections with HIV, and how to access cervical cancers services in your country? Please explain your answer.
- f. In your opinion, are cervical cancer services in your country easily accessible to all, regardless of a woman's social or economic status?
- g. Is there any another information relevant to cervical cancer services in your country that you would like to highlight?

## Annexure two – Study design, methodology and demographic characteristics of the participants

### Background – Zambia

Field work was conducted in Zambia from 30 November 2011 to 7 December 2011. Eight focus group discussions, comprised of 95 women, were convened: five in the greater Lusaka area and three in Chipata in the Eastern Province. Lusaka is the capital city of Zambia.

The Coalition of Zambian Women Living with HIV and AIDS (COZWHA) facilitated access to women for seven of the focus group discussions, while the last focus group discussion was impromptu and was comprised of employees of a local radio station in Chipata. The group at the radio station included one man; however his views have been excluded from the analysis of the research. Figure 1 below shows the schedule of focus group discussions held.

**Figure 1: Schedule of focus group discussions held in Zambia**

	Location/Name of Support Group	Number of participants	Date
1	Kanyama	13	30 November 2011
2	Matero	13	1 December 2011
3	Kamwala	9	1 December 2011
4	Kabangwe	11	2 December 2011
5	Kalingalinga	15	2 December 2011
6	Chipata 1	15	6 December 2011
7	Chipata 2	15	7 December 2011
8	Chipata local radio station employees	4	7 December 2011
	Total number of participants	95	

Kanyama, Matero, Kamwala, Kabangwe and Kalingalinga are townships and peri-urban areas in greater Lusaka.

### Background – Namibia

The field research in Namibia was conducted from 31 January 2012 to 3 February 2012. Seven focus group discussions, comprised of 86 women, were convened: three in Windhoek; two in Okahandja; and two in Otjiwarongo. Windhoek is the capital city of Namibia. Okahandja and Otjiwarongo are towns in Otjozondjupa region in central Namibia, north of Windhoek.

The Namibian Women’s Health Network (NWHN) facilitated access to women for the Windhoek groups. Participants in Windhoek were mostly from support groups affiliated to the NWHN in the Katutura township. The Okahandja women were mostly from the Oshetu township. The Otjiwarongo participants were mostly from Orwetoveni and Tsaraxa-eibe townships. The NWHN organised the logistics of the group discussions in Okahandja and Otjiwarongo, but participants were recruited through other local partners. Figure 2 below shows the schedule of the focus group discussions.

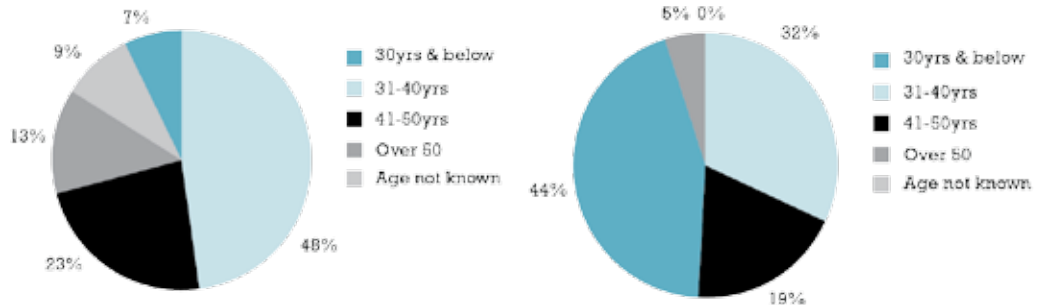
**Figure 2: Schedule of focus group discussions held in Namibia**

	Location/Name of Support Group	Number of participants	Date
1	Windhoek 1	15	31 January 2012
2	Windhoek 2 (Young women’s group)	12	31 January 2012
3	Okahandja 1	12	1 February 2012
4	Okahandja 2	15	1 February 2012
5	Otjiwarongo 1	11	2 February 2012
6	Otjiwarongo 2	12	2 February 2012
7	Windhoek 3	9	3 February 2012
<b>Total number of participants</b>		<b>86</b>	

**Age Range**

The participants ranged from 19-66 years (see Figures 3a & 3b below).

**Figure 3a: Age range of participants in Zambia**      **Figure 3b: Age range of participants in Namibia**

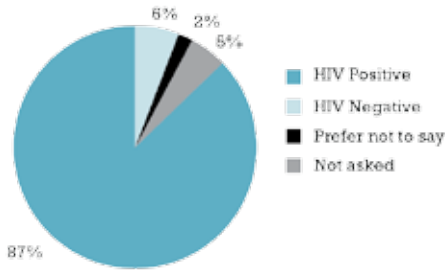


**HIV status**

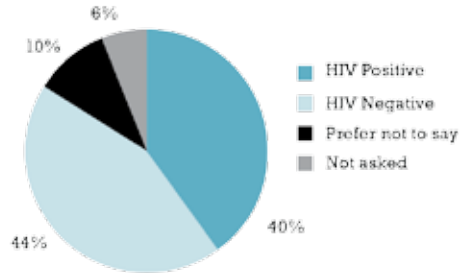
In Zambia, the majority of the research participants (87%) were women living with HIV, while in Namibia only 40% reported being HIV positive (see Figures 4a & 4b).



**Figure 4a: HIV status of participants in Zambia**



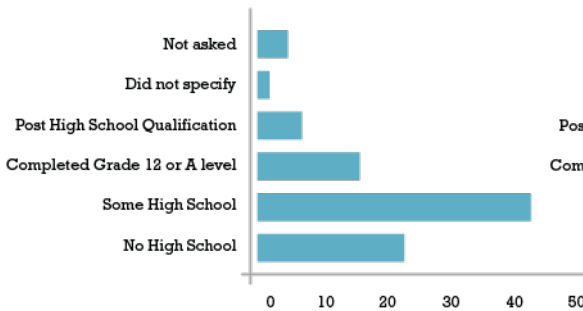
**Figure 4b: HIV status of participants in Namibia**



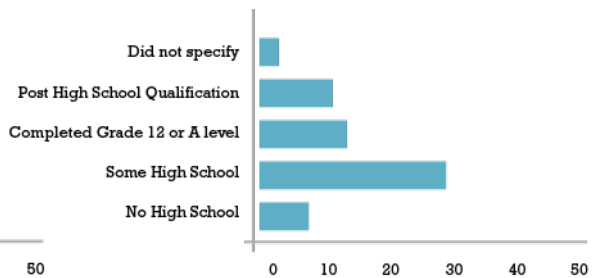
**Employment and socio-economic status**

The women interviewed were mostly from townships and peri-urban areas. Most of the participants were either unemployed or employed in low income, unskilled work (see Figures 5a, 5b, 6a & 6b below).

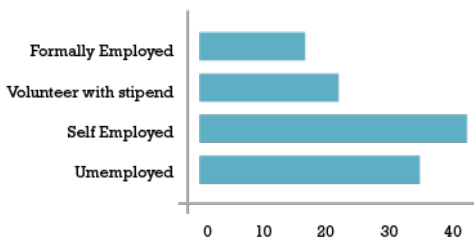
**Figure 5a: Level of education - Zambia**



**Figure 5b: Level of education - Namibia**



**Figure 6a: Employment status - Zambia**



**Figure 6b: Employment status - Namibia**



**Methodology**

Participants in the focus group discussions were asked to fill out a demographics data form upon which the figures and tables in this section are based. This data should not be used to make statistical extrapolations.

The focus group discussions covered the following issues:

- Levels of information and understanding of cervical cancer in general and its linkages with HIV, in particular.
- Experiences in accessing prevention services, primarily vaccines and screening.
- Experiences in accessing treatment for pre-cancerous lesions and cervical cancer.
- Experiences with advanced lesions or invasive cervical cancer.
- Other issues arising in the course of the discussion.





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