# Planning and Implementing Cervical Cancer Prevention and Control Programs



## A MANUAL FOR MANAGERS



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International
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# Planning and Implementing Cervical Cancer Prevention and Control Programs

A MANUAL FOR MANAGERS



Alliance for Cervical Cancer Prevention

2004

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#### **Foreword**

Cervical cancer, the second most common cancer among women worldwide, is an important public health issue. There were more than 493,000 new cases diagnosed and 273,500 deaths from cervical cancer in 2000. Approximately 85% of these deaths occurred in developing countries, and in some parts of the world cervical cancer claims the lives of more women than pregnancy-related causes. This condition affects not only the health and lives of women, but also their children, families, and their community. This extended impact is often undervalued when setting health priorities and requires greater consideration by policymakers.

We have the tools to act. Cervical cancer is one of the most preventable and treatable cancers, since it takes many years to develop from detectable precursor lesions. We have evidence-based interventions for effective early detection and treatment. This knowledge has been used in many developed countries by well-organized programs over the past 50 years. These efforts have resulted in a remarkable reduction in mortality and morbidity from cervical cancer.

Over the same period, however, we have seen little or no change in developing countries. Some of the main barriers here are the lack of awareness among stakeholders, lack of cervical cancer control programs and absence of country-tailored guidelines for best practice of cervical cancer prevention and control.

The World Health Organization (WHO) welcomes this initiative from the Alliance for Cervical Cancer Prevention (ACCP) to provide a manual for program managers at regional and local levels in developing countries. It draws upon their collective experience from implementing research and demonstration projects using new approaches to screening and treatment, and it does so in a variety of geographic and sociocultural settings and for a range of resource levels.

This general, how-to manual responds to the fundamental challenge of moving from policy to actually organizing, implementing, and monitoring newly developed programmes or strengthening existing cervical cancer prevention and control programs. It complements WHO's managerial guidelines for National Cancer Control Programs, and WHO publications on Cervical Cancer Screening in Developing Countries, the International Agency for Research on Cancer (IARC)/WHO Handbooks of Cancer Prevention, Volume 10: Cervix Cancer Screening, and the upcoming WHO Comprehensive Cervical Cancer Control: A Guide for Essential Practice for health care providers.

The ACCP manual is part of a comprehensive resource package based on current evidence and encompassing policy, clinical practice, and service delivery. The package is an ideal toolset for WHO Member States to help increase the effectiveness of their efforts in their fight against cervical cancer.

Catherine LeGales Camus Assistant to the Director General Noncommunicable Diseases and Mental Health Joy Phumaphi Assistant to the Director General Family and Community Health

#### About the Alliance for Cervical Cancer Prevention

The Alliance for Cervical Cancer Prevention (ACCP) consists of five international health organizations—EngenderHealth, the International Agency for Research on Cancer (IARC), JHPIEGO, the Pan American Health Organization (PAHO), and PATH—with the shared goal of preventing cervical cancer in developing countries. Alliance partners work to identify, promote, and implement cervical cancer prevention strategies in low-resource settings, where cervical cancer prevalence and mortality are highest. For more information on the ACCP's work and publications, please visit www.alliance-cxca.org.

# **ACCP** partner organizations

#### **EngenderHealth**

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EngenderHealth works worldwide to improve the lives of individuals by making reproductive health services safe, available, and sustainable. They provide technical

assistance, training, and information, with a focus on practical solutions that improve services where resources are scarce. EngenderHealth believes that individuals have the right to make informed decisions about their reproductive health and to receive care that meets their needs. They work in partnership with governments, institutions, and health care professionals to make this right a reality.

#### International Agency for Research on Cancer (IARC)

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The International Agency for Research on Cancer (IARC) is part of the World Health Organization. IARC's mission is to coordinate and conduct research on the causes of human cancer and the mechanisms of carcinogenesis, and to develop scientific strategies for cancer control. The agency is involved in both epidemiological and laboratory research and disseminates scientific information through publications,

meetings, courses, and fellowships. The agency's work has four main objectives: (1) monitoring global cancer occurrence, (2) identifying the causes of cancer, (3) elucidating the mechanisms of carcinogenesis, and (4) developing scientific strategies for cancer control.

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J H P I E G O JHPIEGO, an affiliate of Johns Hopkins University, builds global and local partnerships to enhance the quality of health care services for women and families around the

world. JHPIEGO is a global leader in the creation of innovative and effective approaches to developing human resources for health.

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The Pan American Sanitary Bureau (PASB), the oldest international health agency in the world, is the Secretariat of the Pan American Health Organization (PAHO). The bureau is committed to providing technical support and leadership to PAHO member

states as they pursue their goal of health for all and the values therein. PASB will be the major catalyst for ensuring that all people of the Americas enjoy optimal health and contribute to the well-being of their families and communities. The mission is to lead strategic collaborative efforts among member states and other partners to promote equity in health, to combat disease, and to improve the quality of, and lengthen, the lives of the peoples of the Americas.

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PATH is an international, nonprofit organization that creates sustainable, culturally relevant solutions, enabling communities worldwide to break longstanding cycles of poor health. By

collaborating with diverse public- and private-sector partners, PATH helps provide appropriate health technologies and vital strategies that change the way people think and act. PATH's work improves global health and well-being.

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#### **About the Manual**

Unlike most other cancers, cervical cancer can be prevented through screening programs designed to identify and treat precancerous lesions. Still, more than 490,000 new cases of cervical cancer occur among women worldwide each year (Ferlay et al. 2004). Approximately 80% of all cases of cervical cancer worldwide occur in less-developed countries, because prevention programs are either non-existent or poorly executed. In response to this situation, the ACCP has collaborated in over 50 countries to:

- Assess innovative approaches to screening and treatment.
- Improve service delivery systems.
- Ensure that community perspectives and needs are incorporated into program design and used to develop appropriate mechanisms for increasing utilization.
- Heighten awareness of cervical cancer and effective prevention strategies.

Planning and Implementing Cervical Cancer Prevention and Control Programs: A Manual for Managers has been developed to help management teams plan, implement, and monitor cervical cancer prevention and control services. These teams consist of program directors, district and facility managers, supervisors, trainers, administrators, and technical advisors, depending on the different countries or programs. Ultimately, this manual aims to contribute to global efforts to improve women's health by promoting appropriate, affordable, and effective service delivery mechanisms for cervical cancer prevention and control.

The manual focuses on the generic program elements crucial to the success of cervical cancer prevention and control programs and deals with the full continuum from prevention via screening and treatment to palliative care. It presents various service delivery options applicable to different geographic and cultural settings, and to a range of resource levels. Management teams will need to select program approaches that best suit their specific setting and program goals.

This manual is written on the assumption that certain key decisions have already been made by national or subnational policymakers about the specifics of the cervical cancer prevention program that will be put in place in their country, region, state, or province. Such decisions include what screening and treatment options and service delivery approach to use, target age group, coverage goals, screening frequency, regulations permitting providers at various levels to perform necessary procedures, and whether to establish vertical or integrated programs. Therefore, detailed information on guidelines for clinical practice and policy decisions for cervical cancer prevention and control are not included in this document. For such information, the reader should refer to documents such as the World Health Organization's (WHO) forthcoming publication, Comprehensive Cervical Cancer Control: A Guide for Essential Practice, the International Agency for Research on Cancer's (IARC) forthcoming Handbooks of Cancer Prevention, Volume 10: Cervix Cancer Screening, and WHO's National Cancer Control Programmes: Policies and Managerial Guidelines. However, basic information is provided here—e.g., features

and resources required for the various screening and treatment options and service delivery approaches—to assist the management team in implementing the policy decisions.

The four parts of this manual provide the information required for the key tasks to be carried out by management teams. Although the chapters follow a logical sequence for planning and implementing a program, each chapter can also be read independently, with cross-referencing where appropriate between the chapters.

#### Countries in which ACCP activities have been conducted

**Africa:** Angola, Burkina-Faso, Cameroon, Congo, Ethiopia, Ghana, Guinea, Kenya, Malawi, Mali, Mauritania, Niger, South Africa, Sudan, Tanzania, Uganda, and Zimbabwe

Latin America and the Caribbean: Antigua and Barbuda, Argentina, Bolivia, Colombia, Dominican Republic, El Salvador, Guatemala, Honduras, Jamaica, Mexico, Nicaragua, Panama, Paraguay, Peru, Suriname, Trinidad and Tobago, and Venezuela

South and South East Asia: India, Laos, Nepal, Thailand, and Vietnam

**Eastern Europe and Central Asia:** Albania, Armenia, Bulgaria, Georgia, Kazakhstan, Kyrgyzstan, Lithuania, Macedonia, Moldova, Mongolia, Russia, Serbia and Montenegro, and Ukraine

# **Executive Summary**

Cervical cancer continues to claim the lives of tens of thousands of women who could have been saved through relatively simple screening for and treatment of precancerous lesions. This tragedy is particularly stark in developing countries, where the burden of disease is heaviest and access to effective prevention services is quite limited. Since 1999, the Alliance for Cervical Cancer Prevention (ACCP) has been implementing research and demonstration projects in many limited-resource countries to characterize the key clinical and programmatic aspects of effective cervical cancer prevention. This document aims to help management teams at the national or subnational level to plan, implement, and monitor cervical cancer prevention and control services. Ultimately, the manual aims to contribute to global efforts to improve women's health by promoting appropriate, affordable, and effective service delivery mechanisms for cervical cancer prevention and control.

#### Part One: Background

Cervical cancer screening and treatment are justified based on the principles of public health screening. The slow progression of precancerous lesions to cervical cancer provides a window of ten years or more to detect and treat the lesions, thus preventing their progression to invasive cancer. Effective cervical cancer prevention programs can be implemented in low-resource settings and should focus on three critical factors: achieving high screening coverage, offering an effective and acceptable test, and ensuring appropriate treatment of test-positive women.

Various cervical cancer screening, diagnostic, and treatment methods are currently being used in developed and developing countries. Each has strengths and limitations that need to be considered in the national policy-level decisions about which methods to use. Cytology, the screening test most commonly used in developed countries, requires multiple visits by the client, screening at regular intervals, and sufficient laboratory infrastructure. These are barriers that can, and indeed have, limited the effectiveness of cervical cancer prevention in low-resource countries.

Alternatives to the traditional screening approaches exist. For example, visual screening methods such as visual inspection with acetic acid (VIA) or visual inspection with Lugol's iodine (VILI) are low-cost approaches with an immediate result. Test specificity, however, is moderate, and so a considerable proportion of women tested with VIA or VILI will be unnecessarily treated or referred for further management. Human papillomavirus (HPV) DNA testing, another alternative screening approach, is a new technology that has better sensitivity than cytology and visual tests and has moderate specificity, but technical, cost, and infrastructure requirements can make it difficult to implement.

Screening methods should be combined with relatively simple, safe, and effective outpatient methods for the treatment of precancer, such as cryotherapy or loop electrosurgical excision procedure (LEEP). Cryotherapy can be performed by physicians and non-physicians, at all levels of health care facilities; it has been shown to have very low morbidity and is acceptable to women, their partners, and providers in a variety of low-resource settings. LEEP is usually performed by physicians with colposcopic guidance and requires local anesthesia, as well as a continuous supply of power and relatively more sophisticated equipment. The major practical difference between the two methods is that LEEP involves excision of the tissue

and hence provides a tissue specimen that allows for histological verification of the diagnosis. On the other hand, cryotherapy is an ablative method that can be used to destroy tissue and leaves no sample for histology.

When screening tests with the inherent potential for overtreatment, such as visual methods or HPV testing, are combined with an outpatient treatment method that is safe, relatively inexpensive, and acceptable, the overall benefit can outweigh the limitations. Irrespective of the screening and treatment methods chosen, the focus should be on linking screening services with precancer treatment services in order to increase women's access to these services. This manual presents various service delivery options applicable to different geographic and cultural settings and to a range of resource levels, keeping in mind that reducing delays and the number of clinic visits for screening, treatment, and follow-up increases program effectiveness. Managers will need to select program approaches that best suit their specific setting and program goals.

Obtaining widespread coverage of the target population is essential and is most readily achieved through well-managed and coordinated prevention programs. If a situation analysis examining country needs and resources suggests that it is reasonable to invest in a cervical cancer prevention program, national policy decisions will need to be made regarding the types of screening and treatment methods to be used, the age to initiate screening, how often to screen, and the desired population coverage level. In addition, sufficient resources will need to be committed to all aspects of cervical cancer prevention and control. This manual offers programmatic guidance to the management team with the assumption that these policy decisions have already been established. It focuses on the program elements crucial to the success of a cervical cancer prevention effort regardless of the screening and treatment approaches used, and discusses the continuum from prevention by screening and treatment to palliative care.

#### Part Two: Planning and Managing a Program

During the policy phase a program coordinator will be designated with the appropriate mandate, authority, and resources to direct the program. The program coordinator should establish a multidisciplinary management team, and the coordinator and the team together should be accountable for directing the program. The multidisciplinary group should include clinical, administrative, and training specialists who are actively involved in the planning, implementation, and evaluation of a cervical cancer prevention program. Sufficient time should be allowed to prepare a careful program plan and budget based on an assessment of local needs and capacities. The plan should ensure that the three components of service delivery—community information and education (I&E), screening services, and diagnostic and/or treatment services—are closely linked. Program policy, training, and monitoring and evaluation provide the programmatic foundation that is essential for success.

Engaging key stakeholders in planning a new program or strengthening existing services is a critical first step to establishing an effective, sustainable cervical cancer prevention effort. Their input can be invaluable, and their involvement at the earliest stages can ensure their commitment to and support for program activities.

A local needs assessment examining technical and infrastructural capacities and information needs enables the management team to identify what inputs are

required to achieve the objectives of a cervical cancer prevention program. The assessment is best conducted through a participatory process involving a multidisciplinary team of stakeholders and obtaining the perspectives of the people involved in providing and those receiving prevention services. Based on the findings of the needs assessment and cost-effectiveness considerations, the management team can elaborate a program plan that describes a step-by-step process for reaching the program's goals of achieving high screening coverage, offering a high-quality and effective screening test, and ensuring that women with positive screening test results receive treatment. The management team's role is to map out local strategies that cover all programmatic areas, including defining local programmatic targets, developing local service delivery strategies, and determining the equipment, training, and resources needed at each site.

Building capacity and systems for service delivery, supervision, monitoring, and evaluation are essential prior to implementing the program. This includes developing all program materials; distributing all equipment and supplies; orienting community, stakeholders, and staff; ensuring providers are trained and available; creating systems for ensuring quality; and setting up an information system. Local area supervisors should be designated to oversee implementation and to coordinate with the management team.

#### Part Three: Implementing Key Aspects of a Program

#### **Delivering Clinical Services and Strengthening Linkages**

The main goal of service delivery is to enable eligible women to have maximum access to quality cervical cancer screening and treatment services. Women in many countries—particularly in rural areas—have limited access to health services. Simply making the services available, however, is insufficient to ensure that they are used. Services need to be accessible, acceptable, affordable, and reliable. For example, programs that reduce the number of clinic visits required for screening, treatment, and follow-up make it easier for women to receive the care they need, improve follow-up rates, and reduce program costs.

Cervical cancer prevention services include counseling, a screening test (with or without a diagnostic test), and precancer treatment for women who test positive. These services can be provided at various levels of health facilities by a wide range of health personnel. Programs can implement a health facility-based (static) approach, a mobile (outreach) approach, or combine the two approaches. In addition, a well-functioning referral network is essential to ensure continuity of care for women needing additional diagnostics and treatment. Trained community health workers/volunteers can be engaged to build and maintain links with the community—to encourage women to utilize the service, to track women who need to be treated and followed up, and to provide community-based palliative care. Lastly, to ensure availability and reliability of services, an efficient supply distribution and logistics chain should be in place.

#### **Providing Information and Counseling to Address Community and Client Needs**

To increase use of cervical cancer prevention services, an I&E plan—combining community-, facility-, and media-based strategies—should be implemented to inform women in the target age group and their partners about the benefits and

availability of cervical cancer prevention services. Direct contact between those in the target population and health workers or peer educators is often more effective in increasing use of services than short-term media activities. Group education, followed by individual counseling, can address clients' information and emotional needs, motivate them to follow treatment recommendations, and establish a satisfied clientele who will encourage other women to attend. Printed materials are helpful for education and counseling, but they should not replace direct provider contact.

#### **Training: Ensuring Performance to Standard**

The goal of training in a cervical cancer prevention program is to ensure that there are sufficient competent staff to attract women to services, screen eligible women with an appropriate test, and treat eligible test-positive women. A training plan—specifying who, what, how, where, and when training will be conducted, plus how much it will cost—should be based on programmatic goals, with special attention given to achieving coverage and maintaining quality of care. Competency-based training that includes a combination of didactic, simulated, and hands-on (practical) approaches enables providers to confidently offer the services. Clinical training should be conducted just before launching services; a long delay between training staff and providing services to the clients could result in a loss of skills. To sustain the program, a system should develop and support an in-country pool of trainers capable of training new providers. This system would promote the transfer of learning through post-training follow-up, including refresher courses.

#### **Improving Program Performance**

Program performance means progress towards achieving defined programmatic targets, such as screening coverage and treatment of all women who test positive. Monitoring and evaluation are essential to ensure that all aspects of care function effectively and efficiently. It should be a continuous process and derive from the interaction of information systems, quality assurance systems, and self-assessment by health workers through a participatory quality improvement process.

A health information system (HIS), based on valid and measurable indicators, is an essential tool for monitoring and evaluating program performance. Such a system can be managed at the facility or central level. Regardless of which model of HIS is used, good-quality data are essential, which requires that staff are trained in data collection, data entry, and report preparation. Having a staff member responsible for maintaining communication linkages between health facilities, distributing forms, aggregating data, and dispatching reports is key to ensuring the flow and quality of information. Data quality should be emphasized over quantity, and data should be used for monitoring and evaluation or decision-making purposes.

Monitoring should aim to improve the quality of services. Improved quality contributes to efficiency and cost savings, promotes job satisfaction, and attracts clients. Client satisfaction, though difficult to measure, can affect utilization of services, which in turn affects program performance. Qualitative tools and approaches are available and can be used to continuously and proactively monitor services, analyze problems, and develop solutions to improve quality of services.

#### Part Four: Overview of Cervical Cancer Treatment and Palliative Care

Cervical cancer prevention services should be linked with cervical cancer treatment and palliative care services, and wherever possible, integrated into a national cancer control plan.

Information and education activities should create awareness, for both providers and clients, that cervical cancer is often curable with appropriate treatment. The management team should strengthen and increase the availability of radical surgery, if such potential exists, and improve access to available radiotherapy services.

Palliative care services should be strengthened at all levels of health facilities, including community-level care. In addition to managing pain and other cancer symptoms, palliative care includes providing support at the community level to mobilize local resources; establishing links to treatment centers; and offering emotional, social, and spiritual support to terminally ill women and their caregivers. Drug regulation and medical and pharmaceutical policies may unnecessarily restrict access to appropriate medications, particularly in rural areas; these should be evaluated and revised as needed.

#### **Conclusion**

Programs should be planned strategically, be based on realistic assessment of needs and capacities, and utilize the most recent evidence on screening and treatment approaches. The poor performance of cervical cancer prevention programs in some limited-resource settings has most often been the result of poor planning and implementation and lack of systems for ongoing monitoring and evaluation, irrespective of the screening test or treatment methods used. Establishing mechanisms and processes to support and sustain each component of a program will go far to ensuring that services are effective, accessible, and acceptable to women who need them.

Part One of this manual provides background information upon which cervical cancer prevention programs can be based.

**Chapter 1** includes information on the magnitude of the problem, the natural history of the disease, screening and treatment methods, and the rationale for implementing a prevention program.

**Chapter 2** offers an overview of policy issues that most directly affect service delivery and program management. Though all individuals responsible for planning and implementing a program may not be involved in making policy-level decisions, they must be aware of and understand the policies that will impact program effectiveness.

# Rationale for Cervical Cancer Prevention

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#### **Key Messages**

- Cervical cancer screening and treatment are justified, based on the general principles of public health screening.
- Unlike many other cancers, cervical cancer is mostly preventable.
   Because of the slow progression of cervical precancer to cervical cancer, there is a window of up to ten years or more to detect and treat precancerous lesions and prevent their progression to invasive cancer.
- Various screening tests are available. All options for screening and for treatment of cervical precancer have strengths and limitations that need to be considered during policymaking, planning, and implementation phases of cervical cancer screening programs.
- Regardless of the screening test used, the focus should be to maximize
  coverage and link screening and treatment services. The feasibility of
  the different approaches for linking screening and treatment depends
  upon available resources in the given setting.
- Cryotherapy can be performed by physicians and non-physicians, at all levels of health care facilities. It has been shown to be safe and acceptable to women, their partners, and providers.

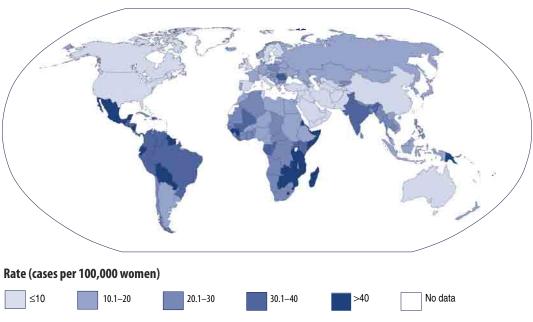
#### Introduction

To assist the management team in building support for prevention efforts, this chapter presents basic information about the burden of disease from cervical cancer and its natural history. It also discusses available methods for the prevention of cervical cancer—screening tests, outpatient methods for treatment of precancer, and management approaches for women with abnormal tests. It is beyond the scope of this document to provide detailed technical information on different screening tests and treatment options or to provide specific guidance on how to decide which would be best suited to any given setting. Additional information can be found in the Further Reading section of each chapter of this manual.

#### **Burden of Disease**

Cervical cancer is the most common cause of cancer deaths among women in developing countries (Ferlay et al. 2004), despite the fact that cervical cancer is preventable. The incidence of cervical cancer by country is shown in Figure 1.1. It should be noted that data on cervical cancer incidence and mortality are more accurate in countries that have cancer registries. Accurate data are not available from most developing countries, and underreporting is high.

**FIGURE 1.1.** Estimated age-standardized incidence of new cervical cancer cases per 100,000 women in 2002



Source: Adapted from Ferlay 2004.

In South Asia and Latin America the rate of cervical cancer has declined slightly over the last two decades or has remained stable, but incidence rates are increasing in sub-Saharan African countries such as Uganda, Mali, and Zimbabwe (Parkin et al. 2001, Parkin et al. 2002, Wabinga et al. 2000). As shown in Table 1.1, in some developing countries such as Argentina, Chile, China, Peru, South Africa, and Thailand, cervical cancer kills more women than maternal mortality (Parkin et al. 2002, WHO 2001a).

**TABLE 1.1.** A comparison of deaths from cervical cancer and maternal mortality in selected developing countries in 2000

Country	Cervical cancer deaths	Maternal deaths
Argentina	1,679	590
Brazil	8,286	8,700
Chile	931	90
Peru	2,663	2,500
South Africa	3,681	2,600
China	25,561	11,000
India	74,118	136,000
Thailand	2,620	520

Sources: Ferlay et al. 2004, AbouZahr and Wardlaw 2004.

#### **Natural History of Cervical Cancer**

Understanding how cervical cancer develops is essential to designing effective interventions to prevent deaths from this disease. More than 99% of cervical cancer cases and its precursors are related to infection with HPV, a sexually transmitted infection (STI) that is mostly asymptomatic (Walboomers et al. 1999). HPV is the most common STI worldwide, affecting an estimated 50 to 80% of sexually active women at least once in their lifetime (Koutsky 1997, Crum et al. 2003). Women are mostly infected with HPV in their teens, 20s, or early 30s. Cervical cancer is essentially a rare complication of a common STI.

Currently more than one hundred types of HPV have been identified, of which more than 30 types are known to cause genital infection. These are broadly classified as high-risk and low-risk for cervical cancer, with approximately a dozen types considered high-risk (some of the low-risk types are associated with genital warts). Infection of the cervix with high-risk types of HPV can lead to cervical abnormalities which, left untreated, progress to cervical cancer in some women (see Figure 1.2). Most HPV infections are transient, however, meaning that the body's defense mechanisms eradicate them, without posing any risk of progressing to cancer (Elfgren et al. 2000, Ho et al. 1998, Nobbenhuis et al. 1999).

For reasons that are not fully understood, approximately 5% to 10% of women infected with high-risk types of HPV develop persistent infections. Evidence shows that these women have an increased risk of developing high-grade precancerous lesions, and, if the lesions are not treated, cervical cancer (Bosch et al. 2002, Ho et al. 1998, Hopman et al. 2000, Muñoz and Bosch 1996, Nobbenhuis et al. 1999, Schiffman et al. 1993, Walboomers et al. 1999). It is not possible to predict in which women precursor lesions will progress to cancer, because the environmental and host immunological factors associated with progression to cancer are also not fully understood.

Transient Infection

Mild cytologic abnormalities

Initial infection

Progression

Progression

Regression

Regression

Precancerous

Invasion

Cancer

**FIGURE 1.2.** The natural history of cervical cancer

Photo source: Wright TC Jr, Schiffman M. Adding a test for human papillomavirus DNA to cervical-cancer screening. *New England Journal of Medicine*. 2003;348(6):489–490. ©2003 Massachusetts Medical Society. All rights reserved.

Table 1.2 summarizes information on HPV infection, cervical precancer, and invasive cancer. HPV infection can lead to low-grade lesions. Most of these lesions either regress on their own or do not progress to high-grade lesions or cancer (PATH 2000). High-grade lesions can develop directly from persistent HPV infection or from low-grade lesions (Cox 2001, PATH 2000). Some high-grade lesions will progress to invasive cancer over a period of up to ten years. Therefore, there is ample time to identify and treat infected women before cervical cancer develops (Miller 1992, Jenkins et al. 1996). Most low-grade lesions either regress on their own or do not progress to high-grade lesions or cancer (PATH 2000). Cervical cancer most often develops in women after age 40, and the incidence is highest among women in their 50s and 60s (Miller 1992, Parkin 1997).

**TABLE 1.2.** HPV infection, cervical precancer, and invasive cervical cancer

HPV infection	Low-grade lesions	High-grade lesions	Invasive cancer
HPV infection is extremely common among women of reproductive age. The infection can persist, lead to cervical abnormalities, or resolve on it own.	Low-grade lesions are usually temporary and disappear over time. Some cases, however, progress to high-grade lesions.	High-grade lesions, the precursor to cervical cancer, are significantly less common than low-grade lesions. High-grade lesions can develop from low-grade ones or directly from persistent HPV infection.	Invasive cancer develops over the course of several years and is most common among women in their 50s and 60s.

Source: Adapted from PATH 2000.

The understanding that HPV is the necessary but not solely sufficient precursor to cervical cancer has focused attention on the potential for primary prevention. Risk factors for HPV—such as early onset of sexual activity, multiple lifetime sexual partners (of a woman or her partners), and history of other STIs—generally reflect sexual activity. Therefore, primary prevention efforts have focused on reducing infection by reducing the number of sexual partners and encouraging the use of barrier contraceptives, especially condoms (Centers for Disease Control and Prevention 2004, Lytle et al. 1997, Weaver et al. forthcoming).

Limited data suggest, however, that these efforts would achieve only minimal effect; in particular, research has demonstrated a weak association between the use of barrier contraceptive methods and a decreased risk of HPV infection (Kjaer et al. 1997, Lytle et al. 1997, Lazcano-Ponce et al. 2001, Molano et al. 2002, Plummer and Franceschi 2002, Shepherd et al. 2000a,b). This is likely because men and women infected with HPV can harbor the virus both on the internal and external genitalia, including areas not protected by condoms. Further, individuals can harbor HPV infection for long durations without knowing they are infected; therefore, even mutually monogamous couples may transmit infections obtained in a previous relationship to a current partner.

The most promising approach to primary prevention of cervical cancer is through development and broad provision of effective HPV vaccines. It is expected that

prophylactic vaccines against HPV 16 and 18 (which account for about 70% of cervical cancer cases) are likely to become commercially marketed in some developing countries before 2010. Early data suggest that these vaccines are likely to be effective in preventing certain types of HPV infection and precancer (cervical intraepithelial neoplasia [CIN]); their long-term impact on cancer rates will not be known for many years after introduction (Koutsky et al. 2002). Even after these prophylactic vaccines become available, it will be important to continue screening and treatment programs for the many women already exposed to HPV as well as for women infected with carcinogenic HPV types other than HPV 16 or 18.

#### **Methods of Cervical Cancer Prevention**

#### **Screening tests**

Screening involves testing a target group (in this context, women) who are at risk for a given disease (in this context, cervical precancer). The aim of screening is to detect and treat those people identified as having early signs of the disease, usually by means of an inexpensive, accurate, and reliable test that can be applied widely. There are several cervical cancer screening tests in use or being studied around the world. Cervical cytology has been in use for the past 50 years. Newer screening tests are HPV DNA testing and visual screening tests. Each of these tests has potential advantages and disadvantages. The tests are briefly described below, with some additional technical information, plus strengths and limitations, presented in Appendix 1.1. No screening test is perfect, and the advantages and disadvantages need to be carefully weighed in any particular setting when deciding which test or tests to use.

#### **Traditional screening methods**

**Cervical cytology** Conventional cervical cytology—also referred to as the Papanicolaou test, Pap test, Pap smear, and cervical smear—detects abnormal cells in a sample taken from the cervix. It involves performing a speculum examination to expose the cervix and the os, and collecting cervical cells using a wooden or plastic spatula, broom, or brush. These cells are then smeared and fixed on a glass microscope slide. The slides are transported to a laboratory where they are usually processed manually. Each slide is then evaluated under the microscope by a trained cytology technician. This multistage process can take several weeks before the results are available to the client, although in well-organized programs results can be available sooner.

Liquid-based cytology (LBC) testing is a new technique that provides a uniform thin layer of cervical cells without debris. It is a more expensive test than conventional cytology and requires additional supplies and sophisticated equipment to process the smear. The impact of LBC on cancer incidence and mortality remains to be established, as does its cost-effectiveness. For further reading on cytology and cytology laboratory services, refer to WHO, *Cytological Screening in the Control of Cervical Cancer: Technical Guidelines* (1988), and to PAHO/WHO, *Pan American Cytology Network*. *An Operations Manual* (2001).

Existing cervical cancer prevention programs are nearly all cytology-based. Cervical cytology is the screening test that has been most widely used since the middle of

the twentieth century in developed countries and in those developing countries where screening is available. Well-organized and well-implemented cytology-based screening programs that screen women at regular intervals have been associated with measurable reductions in cervical cancer incidence and mortality when screening coverage and the treatment rate of women with abnormal findings are high. However, sensitivity and specificity of cytology have not been consistently high in a range of settings, especially in those with limited resources (see Appendix 1.1). Cytology-based programs can be implemented effectively only if infrastructure and laboratory quality assurance requirements are consistently met.

#### **New screening methods**

**HPV DNA test** The currently available test, Hybrid Capture 2, determines if one or more of the high-risk types of HPV virus (those associated with cervical cancer) are present in a cervical specimen. HPV DNA testing usually involves a speculum exam to obtain a sample of cervical cells using a brush or swab. The sample is transported to a laboratory for processing. Where such laboratory services have been established, an automated system can process 70 to 90 specimens at a time, requiring a total processing time of about seven hours. The results can potentially be returned to the service site in a day. Use of self-collected samples, where no speculum exam is needed, has been explored, and it has been shown that self-collected specimens have adequate sensitivity and are a culturally acceptable method in some settings (Wright et al. 2000, Dzuba et al. 2002).

Although the technical, cost, and infrastructure requirements can make the HPV DNA test difficult to implement, available data suggests that it performs better than cytology and visual tests in detecting precancerous lesions among women in their 30s and 40s (see Appendix 1.1 for general information on test performance). Efforts are ongoing to develop simple, inexpensive HPV DNA tests that can provide quicker results. By 2010, ACCP studies are expected to have evidence on long-term impact of HPV DNA testing on cervical cancer incidence rates.

**Visual tests: VIA and VILI** There are two kinds of visual tests to identify precancerous cervical lesions. In visual inspection with acetic acid (VIA), sometimes referred to as direct visual inspection (DVI), precancerous lesions temporarily appear white after staining with acetic acid (vinegar). Like cervical cytology and HPV DNA testing, VIA involves a speculum examination and exposing the cervix and the os. After swabbing the cervix with 3%–5% acetic acid using a cotton applicator, abnormal areas have a distinctive white appearance.

VIA can be implemented in a wide range of settings. No laboratory processing is required, the results are immediate, and treatment can be provided in the same visit. Due to the subjective nature of visual assessment, it is important to standardize definitions for positive and negative tests, and to give special attention to regular and consistent quality assurance (Denny et al. 2002). While in most studies to date the sensitivity of VIA has been equivalent to or better than cytology, its specificity has been lower (see Appendix 1.1). By 2010, ongoing ACCP studies will provide evidence of the impact of VIA on cancer incidence rates.

The second test is visual inspection with Lugol's iodine (VILI). Like VIA, VILI involves temporarily staining the cervix—this time with Lugol's iodine. Normal cells take up the iodine stain and appear a mahogany-brown color, whereas precancerous cervical lesions appear yellow. Like VIA, results for VILI are immediate, treatment can be provided in the same visit, and it may be implemented in a wide range of

settings. VILI may perform better than VIA, but further evaluation is needed to demonstrate the effectiveness of VILI in a variety of settings, as well as the impact of VILI as a screening test on the reduction of cervical cancer incidence.

#### **Diagnosis and confirmation**

Conventionally, cytology-based screening is linked to treatment through an intermediary diagnostic step using colposcopy, followed by confirmatory biopsy when indicated. Endocervical curettage (ECC) or an endocervical smear can be used to sample the endocervical canal. Laboratory assessment of the tissue samples obtained by biopsy (histology) confirms the presence or absence of CIN in precancer stages and cervical cancer itself.

Colposcopy involves high-powered illuminated magnification of the cervix using a colposcope—a binocular magnifying instrument (see *p. XX*). This enables providers to determine the extent of lesions and is useful in taking biopsies and in providing directed treatment with cryotherapy or loop electrosurgical excision procedure (LEEP). Colposcopy is noninvasive and performed as an outpatient procedure. It does not require anesthesia. Colposcopes are expensive—with cost ranging from US\$800 to \$13,000—and providers require specialized training and experience to use them proficiently. ACCP studies in India and Africa show that including colposcopy as an intermediary step reduces overtreatment; but colposcopy may not be practical in many low-resource settings due to the costs of equipment and training.

#### **Treatment of precancerous lesions**

The ability to offer women appropriate and effective treatment for precancerous lesions is a critical component of a successful cervical cancer prevention program. Safe and effective outpatient methods are preferred for management of precancerous lesions. In many limited-resource countries, however, clinicians lack training and experience and often the essential equipment and supplies required for simple outpatient treatment procedures. Hence they rely on more costly and complex inpatient methods such as cold-knife conization or hysterectomy performed under general or regional anesthesia by skilled specialists. Although these invasive procedures might be appropriate in special circumstances, they should be used judiciously since they can be associated with significant complications, including bleeding, pelvic infection, and injury to adjacent pelvic organs.

Cryotherapy and LEEP are two safe, effective, and relatively simple and inexpensive outpatient methods used for the treatment of precancer. The major practical difference between the two methods is that LEEP involves excision of the tissue and hence provides a tissue specimen that allows for histological verification of the diagnosis. On the other hand, cryotherapy is an ablative method that involves destroying the tissue and thereby leaves no sample for histology (see Table 1.3). Regardless of which outpatient method is used, health care providers should be aware of the implications of treating women living in areas where HIV prevalence rates are high (see box on next page). Use of less-invasive methods requires less infrastructural support, can minimize women's health risks, and decreases health care costs. Simpler methods often are more accessible to women because they can be offered at lower levels within the health care system.

#### **HIV-Specific Treatment Issues**

Precancerous cervical lesions tend to be more prevalent, persistent, and likely to recur in HIV-positive women (Ellerbrock et al. 2003, Tate and Anderson 2002). Therefore, these women should receive special counseling prior to treatment. Women should be advised that cryotherapy and LEEP are likely to be less effective in treating lesions in HIV-positive women and that they will need regular follow-up care. There is some evidence that HIV shedding increases substantially—but temporarily—from the treated area of the cervix following treatment (Wright et al. 2001). Currently there is no conclusive evidence linking HIV transmission with cryotherapy or LEEP; this needs further evaluation. For women requiring treatment, it is essential to counsel the client and her partner on the importance of abstaining from sexual intercourse during the healing period (or using a condom if abstinence is not possible) to protect the woman and her partner from possible increased risk of HIV infection.

#### Cryotherapy

Cryotherapy is a relatively simple procedure that destroys precancerous cells by freezing the cervix, using compressed carbon dioxide ( $\mathrm{CO_2}$ ) or nitrous oxide ( $\mathrm{N_2O}$ ) gas as the coolant. To freeze the lesion, the cryoprobe is placed on the cervix, ensuring that the probe covers the entire lesion. The aim of this procedure is to create an ice ball extending 4–5 mm beyond the lateral margin of the cryoprobe. Cryotherapy is performed using a single-freeze or double-freeze technique. Single freeze involves freezing for three minutes; double freeze involves freezing for three minutes followed by a thaw for five minutes, and then a second freeze for three minutes. The ACCP is conducting a randomized control study comparing single with double freeze to clarify the implications and potential advantages and disadvantages of each; results will be available in early 2005.

Cryotherapy is an outpatient procedure that can be performed easily and quickly (in 15 minutes or less) without anesthesia. It can be safely and effectively performed by general practitioners and non-physicians (Jacobs et al. forthcoming). ACCP studies show that cryotherapy is an acceptable treatment option for women, their partners, and providers (Royal Thai College of Obstetricians and Gynecologists [RTCOG]/JHPIEGO 2003a).

Women undergoing cryotherapy need clear information and support to alleviate possible anxieties about side effects. Many women experience mild discomfort, such as pain or cramping during or within two to three days after the procedure. They may also experience dizziness, fainting, or flushing during or immediately after treatment. The most frequently experienced side effect of cryotherapy is a profuse, watery vaginal discharge for up to four weeks. Although inconvenient, women can effectively manage it by using a clean cloth or sanitary pads to protect clothing.

Complications associated with cryotherapy are minimal. Available data suggest that cryotherapy is safe, with very little risk of major complications (ACCP 2003a). Severe bleeding and pelvic inflammatory disease, two of the most serious

potential complications, are extremely rare in women treated with cryotherapy. There also is no evidence that cryotherapy is linked to cervical stenosis or has any long-term impact on women's fertility or pregnancy outcomes—important considerations when treating women of reproductive age (ACCP 2003a, RTCOG/JHPIEGO 2003b).

Cryotherapy is the most practical treatment approach for most low-resource settings given its simplicity and low cost. In addition, it can be safely performed in primary care settings by non-physicians; so in settings where screening test results are immediately available, women can be treated during the same visit. Other advantages of cryotherapy are that the equipment required is relatively simple, the procedure is easily learned, and it does not require anesthesia or a power supply. One disadvantage of cryotherapy is that because it destroys the tissue, no tissue sample is available to confirm that the entire lesion has been removed. Furthermore, it is not possible to establish whether it is an early invasive lesion requiring further treatment. Cryotherapy is not appropriate for treating large lesions that cannot be covered by the probe or lesions located in the endocervical canal. Also, a regular supply of liquid coolant is necessary.

#### **Loop electrosurgical excision procedure (LEEP)**

Sometimes referred to as large-loop excision of the transformation zone (LLETZ), LEEP utilizes a thin electric wire in the form of a loop to remove the abnormal area of the cervix. The procedure is usually done using colposcopic guidance under local anesthesia in a secondary or tertiary care setting and requires local anesthesia, as well as a continuous power supply. Severe bleeding is a possible complication both during and after the procedure, occurring in 1% to 4% of patients (Mitchell 1998, Wright et al. 1992, Sellors and Sankaranarayanan 2002). More sophisticated equipment is required compared with cryotherapy. Table 1.3 compares cryotherapy and LEEP on key criteria.

Two advantages of LEEP are that it is a simple surgical procedure and that the excised tissue can be sent for histopathological confirmation, which allows the exact nature of the lesion to be determined and unsuspected microinvasions to be detected. However, many developing countries lack access to histology services.

**TABLE 1.3.** Comparison of cryotherapy and LEEP

Indicators	Cryotherapy	LEEP
Effectiveness	86-95%*	91-98%*
Potential side effects	Watery discharge	Bleeding
Anesthesia	None required	Local anesthesia necessary
Tissue sample for histopathology	No	Yes
Power required	No	Yes
Relative cost	Low	High
Level of provider	Physicians and non- physicians	Mostly by physicians

Source: Adapted from Bishop 1995.

#### **Linking screening and treatment**

Regardless of the screening test used, screening must be linked to treatment to ensure program effectiveness. This can be done using the traditional approach (screen, diagnose, confirm, and treat), intermediate approach (screen, diagnose, and treat with post-treatment biopsy confirmation), or the screen-and-treat approach (treatment is based on the results of screening test alone). These approaches are described in detail in Chapter 6.

# **Justification for Cervical Cancer Screening**

The purpose of any type of public health screening is to offer a low-cost, accessible means for determining who in a population is likely to have or develop a certain disease, and to then provide diagnostic testing, appropriate treatment, or both. The general principles of public health screening are described in the box opposite.

<sup>\*</sup>ACCP 2003a, Martin-Hirsch et al. 2004.

#### **General Principles of Screening**

Criteria for deciding whether or not screening is appropriate include:

- Is the disease a public health problem?
- Is the natural history of the disease understood?
- Is there a recognizable latent or early symptomatic stage?
- Is there an acceptable treatment for the disease?
- Is there consensus on whom to treat?
- Are facilities for screening and treatment available and accessible?
- Is there an economic balance between case finding and subsequent medical care?
- Is the program sustainable?

Source: Adapted from PATH 2000.

Cervical cancer screening is justified according to the listed criteria because:

- Cervical cancer is an important public health problem in many resource-poor settings.
- There is a recognized precursor stage (i.e., precancerous lesions) that can be treated in a safe, effective, and acceptable way.
- The time between the appearance of precancerous lesions and the occurrence of cancer is long (about ten years), leaving ample time for detection and treatment.
- Treatment of early lesions is very inexpensive compared to the management of invasive cancer.

Women who have access to effective prevention programs are less likely to develop cervical cancer than women who do not. It is not surprising then that the incidence of cervical cancer varies dramatically between regions of the world, as well as between different socio-demographic groups within a given region. In the mid-1980s, approximately 40% to 50% of women in developed countries had been screened in the preceding five years, compared to only 5% of women in developing countries (WHO 1986). Although these data are old, there are few indications that the situation has changed significantly since then in most developing countries. For example, more recently, only 8% of more than 20,000 South African women 20 years of age and older reported having had a Pap smear in the preceding five years (Fonn et al. 2002). Likewise, in a rural district in India, where more than 120,000 women were interviewed, less than 1% reported having ever been screened. In developed countries where women regularly receive cytologic screening, programs have led to decreased cervical cancer-related mortality (Mitchell et al. 1996, Eddy 1990, IARC 1986a,b). In most developing regions, however, cervical cancer mortality rates have not declined substantially despite attempts to establish screening programs (Beral et al. 1994).

#### **Conclusion**

Cervical cancer is preventable through screening to detect precancerous lesions and appropriate treatment before the lesions develop into cancer. The nature of the disease and the treatment options available justify cervical cancer screening programs, according to general principles of public health screening. Various cervical cancer screening, diagnostic, and treatment methods are currently being used in developed and developing countries. Each method has strengths and limitations that need to be considered in the policy-level decisions about which methods to use. It is important to remember that regardless of the screening and treatment methods chosen, the two must be strongly linked so that women who are identified as having precancerous lesions are able to get the treatment they need to prevent the development of cancer.

### **Further Reading**

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# Appendix 1.1. Characteristics of Screening Tests

		Newer screening tests		
Characteristics	Cervical cytology	HPV DNA test	Visual inspection tests	
			Visual inspection with acetic acid (VIA)*	Visual inspection with Lugol's iodine (VILI)
Sensitivity and speci- ficity for high-grade lesions and invasive	Sensitivity = $47-62\%^{**}$ Specificity = $60-95\%^{**}$	Sensitivity = $66-100\%^{**}$ Specificity = $62-96\%^{**}$	Sensitivity = 67–79%** Specificity = 49–86%**	Sensitivity = $78-98\%^{**}$ Specificity = $73-91\%^{**}$
cancers	Cytology has been assessed over the last 50 years in a wide range of settings in both developed and developing countries.	HPV DNA testing has been assessed over the last decade in many settings in developed countries and relatively few settings in developing countries.	VIA testing has been assessed over the last decade in many settings in developing countries.	VILI testing has been assessed by IARC over the past 3 years in India and 3 countries in Africa. It needs to be evaluated by others in additional settings to confirm the reproducibility of the above results.
Number of visits required for screening and treatment	Requires 2 or more visits.	Requires 2 or more visits.	Can be used in a single-visit approach in setting where outpatient treatment is available.	Can be used in a single-visit approach in setting where outpatient treatment is available.

\*VIA is also referred to as direct visual inspection (DVI).

\*\* Source: Sankaranarayanan et al. forthcoming. Sensitivity is the proportion of individuals correctly identified by the test as having disease. Higher sensitivity means that fewer lessons will be missed (i.e., there will be fewer false negatives). Specificity is the proportion of individuals correctly identified by the test as NOT having disease. Higher specificity means that there will be fewer false positives.

		Newer screening tests		
Characteristics	Cervical cytology	HPV DNA test	Visual inspection tests	
			Visual inspection with acetic acid (VIA)*	Visual inspection with Lugol's iodine (VILI)
Type of provider	Competently trained nurse, nurse midwife, clinical assistant, physician's assistant, general physician, or gynecologist to obtain and fix the specimen.  Competently trained lab technician to process and evaluate the specimen.	Competently trained nurse, nurse midwife, clinical assistant, physician's assistant, general physician, or gynecologist to collect the sample.  Competently trained lab technician to process the specimen.	Competently trained nurse, nurse midwife, clinical assistant, physician's assistant, general physician, or gynecologist to perform and interpret the test.	Competently trained nurse, nurse midwife, clinical assistant, physician's assistant, general physician, or gynecologist to perform and interpret the test.
Strengths	Widely accepted and used for over 50 years, with evidence that reduction in cervical cancer incidence and mortality can be achieved in high-quality programs.  In settings with adequate resources, meets most of the criteria for a good screening test.  Permanent record of the test in the form of a slide.  High specificity.	Test detects 13 oncogenic HPV types (without distinguishing which type[s] are present).  Objective test. Identifies both women with precursor lesions and women who are at a greater risk for developing cervical disease in the future.  A negative test result virtually guarantees that there is no HPV infection or related lesions.  Not affected by presence of cervical or vaginal infections.  High specificity in women over age 35.	Simple procedure needing minimal resources. Immediate results, so immediate treatment is possible. Simple equipment and supplies needed.	Simple procedure needing minimal resources. Immediate results, so immediate treatment is possible. Simple equipment and supplies needed. Easier to detect color changes produced by iodine staining than by acetic acid.

\*VIA is also referred to as direct visual inspection (DVI).

		Newer screening tests		
Characteristics	Cervical cytology	HPV DNA test	Visual inspection tests	
			Visual inspection with acetic acid (VIA)*	Visual inspection with Lugol's iodine (VILI)
Limitations	Subjective test because outcome depends on the technician's interpretation of the results.  Systems are needed to ensure that lab results are returned to the clinic and that women with abnormal findings receive appropriate treatment.  Significant infrastructure requirements and costs, including trained lab technicians.  Potential for mislabeling of samples and damage or loss during transport.  Sampling and lab errors can occur.  Requires a lab quality assurance system.	Systems are needed to ensure that lab results are returned to the clinic and that women with positive test results receive appropriate treatment.  Significant infrastructure requirements and costs, including trained lab technicians.  Potential for mislabeling of samples, lab errors, damage or loss during transport, and breakdown of processing equipment.  Only moderately specific in women younger than age 35.  If treatment is provided based on test results alone, many women are treated unnecessarily because they test positive but do not actually have precancer. This can overload the service site where treatment is being offered.	Subjective test because the outcome depends on the clinician's interpretation of what is seen on the cervix.  Not appropriate for screening post-menopausal women.  VIA-positive lesions are not unique to precancer.  If treatment is provided based on test results alone, many women are treated unnecessarily because they test positive but do not actually have precancer.  This can overload the service site where treatment is being offered.	Subjective test because the outcome depends on the clinician's interpretation of what is seen on the cervix.  Limited data on validity of VILI as a primary screening test. Needs further evaluation.  Staining can persist for 30 to 45 minutes. Therefore, further clinical evaluation, if needed, is delayed.  VILI-positive lesions are not unique to precancer.  Not appropriate for screening postmenopausal women.  If treatment is provided based on test results alone, many women are treated unnecessarily because they test positive but do not actually have precancer. This can overload the service site where treatment is being offered.

 $^\star \rm VIA$  is also referred to as direct visual inspection (DVI).

# **Overview of Policy Considerations**

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#### **Key Messages**

- Effective cervical cancer prevention programs can be implemented in both developed and developing countries.
- Policymakers must be committed to invest in and devote the necessary resources and dedicated staff to program planning, implementation, and monitoring.
- The policy phase should be as participatory as possible, involving key stakeholders and clearly basing policy decisions on the needs and health priorities of the population.
- Cervical cancer screening policies in limited-resource settings should focus on initially screening a high proportion of women in their 30s and 40s at least once using a screening and treatment approach that involves a minimal number of visits.

#### Introduction

According to the WHO managerial guidelines for National Cancer Control Programmes, the key phases in developing a cervical cancer prevention program are policymaking, program planning, and implementation. This manual focuses on the program planning and implementation phase at the subnational level (regional/district/state/provincial) and assumes that policy-level decisions are largely determined before the management team is asked to plan and implement services. Although the management team may not be involved in national-level policy decisions, they must be aware of and understand the policies about the screening and treatment methods to be used; target age group, frequency of screening, and desired population coverage level; maximizing access to health care providers; and vertical or integrated services.

#### The Decision to Develop a Cervical Cancer Prevention Program

The natural history of cervical cancer and the availability of effective screening and treatment methods justify, in principle, investment in cervical cancer prevention programs. ACCP research findings suggest that it is possible in developing countries to implement organized cervical cancer prevention programs that will reduce the burden of disease. However, it is not recommended that screening programs be put into place in any setting unless two conditions are met. First, the incidence of cervical cancer must justify it. Second, the necessary resources must be available and committed for attaining wide screening coverage and ensuring that adequate systems are in place to appropriately manage screen-positive women, in order to achieve program success (WHO 2002a). Therefore, primary policy decisions are whether a cervical cancer prevention program is justified in the given setting and if there is political commitment to dedicate the necessary resources to effectively plan, implement, and monitor such a program.

Selecting appropriate technologies for screening and treating precancer are just the start of a successful program. The resources and requirements for making screening and treatment available and accessible, as well as the willingness and ability of women to use the services, play equally important roles. Implementing an *organized* screening program that addresses these issues is the best way to ensure success. Ideally, an organized screening program should have a population-based cancer registry and a computerized call and recall system, both of which may not be feasible in limited-resource settings. However, a well-managed screening program with coordinated services based on the key characteristics listed in the box below is feasible even in limited-resource settings.

#### **Characteristics of Organized Screening Programs**

An organized cervical cancer screening program has:

- A defined target population.
- Effective recruitment strategies to achieve high coverage.
- A health care system with capacity to screen, follow-up on those screened positive, and provide treatment as indicated.
- A quality assurance system.
- A health information system.
- A management team responsible for planning and implementation.

Source: Quality Management Working Group, Cervical Cancer Prevention Network 1998.

Opportunistic, or spontaneous, screening refers to services provided to women who request it or who are already in a health facility for other services, without any effort to reach a particular population. This has less impact on cervical cancer incidence and mortality and reduces cost-effectiveness (Hakama 1997). A major problem with opportunistic screening is that many of the women who are screened are not in the appropriate age group, since most of the screening is limited to women attending primary health care, antenatal, and family planning clinics. Often in these settings many of the women are less than 30 years old and are not likely to show signs of precancer or have low-grade disease which will regress spontaneously. There are few organized efforts in low-resource settings to ensure that women over the age of 30 are screened (Chirenje et al. 2001, Miller 1992). Consequently, women are not identified until they are at an advanced stage of disease, resulting in high morbidity and mortality (Parkin et al. 1993).

#### Strategic Approach Framework

WHO's strategic approach to the introduction of contraceptive technologies (Simmons et al. 1997) can be adapted to the introduction or strengthening of cervical cancer prevention programs. This approach promotes the concept that appropriate decisions concerning policy and program development should be

based on an understanding of the relationships between the at-risk population, the service delivery system, and the mix of services and interventions being provided. The process also takes into account how these interactions are influenced by the broader sociocultural and political context. This locally led process of program design encourages collaboration and partnership among a broad range of stakeholders concerned about improving the quality of current services or introducing new technologies.

In adapting this strategic approach to the introduction of cervical cancer prevention services, it is recommended that policy-level decisions and planning should address a series of interactions between:

- Women (clients) and the services that are available and accessible to them.
- Women and the screening and treatment technologies, including how acceptable women find the available options.
- Service delivery systems and the screening and treatment technologies, including the ability to successfully introduce new technologies and sustain the services. (See Figure 2.1 below and box on page 22.)

**FIGURE 2.1.** A strategic approach to cervical cancer prevention

Women's perspectives Medical profile Sociocultural and gender influences Community outreach Education WOMEN **TECHNOLOGY SERVICE** Policies, program structure, management Efficacy Availability and accessibility Safety **Ouality of services** Procedures and supplies **Health Information Systems** Laboratories (including quality control) Referrals Costs Qualified providers Acceptability

Source: Adapted from Simmons et al. 1997.

# Strategic Approach to Assessing Cervical Cancer Prevention Programs in Bolivia

The WHO's three-stage Strategic Approach for the Introduction of Contraceptive Technology (Simmons et al. 1997) fosters the participation of local decision-makers, communities, and stakeholders in developing and implementing a strategy for providing and utilizing services. From 2001 to 2002, in an effort to assess the existing cervical cancer prevention and treatment services in Bolivia and to identify appropriate intervention strategies, the Component for the Detection and Control of Women's Cancer of the Bolivian Ministry of Health adapted and initiated the WHO strategic approach. In collaboration with EngenderHealth and PAHO, the ministry instituted the first of the three stages by conducting a situation analysis in four regions of Bolivia. A multidisciplinary team, conducted the situation analysis using semi-structured interviews and observations. A technical workshop was then organized with key stakeholders and together the group developed evidence-based priorities and recommendations to improve services, including future research opportunities, policies, and programmatic interventions. Multidisciplinary involvement enabled the incorporation of many perspectives and encouraged in-country alliances to reinforce and expand ideas for program planning and policy development. This participatory process led to stakeholder ownership of the assessment findings and recommendations in Bolivia.

Source: Bolivia Ministry of Health et al. 2003.



#### **Policy Decisions Concerning Services**

As described in the box that starts below, the policy phase of program development consists of the following steps: confirm political commitment, engage high-level stakeholders, conduct a large-scale situation analysis, develop policies based on the assessed situation, and obtain support for the new policies and resources for programming. While the entire management team is not usually involved in the policy development, it is helpful for the team to understand some of the factors that are considered in policymaking, particularly those decisions that most directly affect service delivery and program management.

#### **Steps in the Policy Phase of Program Development**

#### **Confirm political commitment**

High-level decision-makers must be committed to developing or strengthening a cervical cancer program. This commitment must be reflected in the investment of the necessary resources and designation of a coordinator for cervical cancer prevention with appropriate mandate, authority, and resources to direct the program.

#### **Engage high-level stakeholders**

Policymakers need to identify senior individuals representing the key groups that will be involved in or affected by a cervical cancer prevention program to provide guidance and support for program development. Such individuals should be decision-makers within their own organizations, and should include senior Ministry of Health officials, heads of medical organizations, university professors, heads of nongovernmental organizations (NGOs), and high profile community leaders, particularly representing women's groups.

#### **Conduct situation analysis**

To make decisions about the feasibility and scope of the program, the burden of disease in the population must be determined and the relative importance of cervical cancer compared to other health priorities must be assessed. Existing services that could be utilized for a screening program must be surveyed, and technical resources that are currently available (or can realistically be developed) need to be identified.

#### **Develop policy**

The policies that will govern the services must be determined. These policies should establish the screening and treatment methods to be used, the target age group for screening, the desired population coverage, screening frequency, appropriate provider licensing (e.g., permitting midlevel health providers to perform clinical procedures), and whether the program will be vertical or integrated into other health services. These decisions are made at the national policy level because they require large-scale commitment, support, and allocation of resources. National guidelines and norms should be developed based on these policies.



#### Obtain support for new policy and solicit resources for the program

Resources must be allocated to ensure the program can be adequately implemented. Support from managerial and medical bodies also must be obtained so that they advocate for the new policies and programming within their own spheres of influence.

Source: Adapted from WHO 2002a.

#### Screening and treatment methods

Those responsible for making decisions about what screening and treatment options will be implemented in any country, program, or organization should consider the following when deciding which are most suitable:

- Performance of the screening tests.
- Processing requirements of the tests.
- Safety and effectiveness of the treatment.
- Equipment and supplies required.
- Feasibility of using the screening and treatment options in proposed locations.
- Acceptability of screening and treatment options to women, their partners, and providers.
- Likely impact of the screening and treatment options on the burden of disease.
- Costs involved.

#### Target age group, frequency of screening, and coverage

#### Target age group

When determining the target age group for screening—the most appropriate ages to initiate and to stop screening—the following should be taken into consideration:

- The risk of the disease in various age groups.
- The performance characteristics of the screening tests to be used with respect to various age ranges.
- The availability of resources needed to provide screening and treatment.

According to IARC (IARC Handbooks of Cancer Prevention, Volume 10, forth-coming) screening should initially focus on women in their 30s and 40s—the ages where women are at the highest risk of precancerous lesions but before the incidence of invasive cancer begins to peak. In most countries, the incidence of invasive cervical cancer is very low among women under age 25. Generally, incidence increases thereafter and reaches a maximum in women in their 50s and 60s. Data from cancer registries in developing countries indicate that approximately 70% of confirmed cases occur among women aged 45 or older. Precancerous lesions, however, are generally detectable for ten years or more before cancer develops, with a peak at about age 35. Women over 50 who have never been screened are at relatively high risk of cervical cancer, though women in this age group who have had one or more negative screens in the last ten years are at low risk.

The specific characteristics of different screening tests can help determine the target age group. For example, visual screening methods are most suitable for women under the age of 50, because in older women the squamocolumnar junction recedes into the cervical canal and is difficult to see. HPV DNA testing should be restricted to women over 35 years. In younger women HPV DNA testing has low specificity and therefore produces a high rate of false positive test results (Wright and Schiffman 2003). Cytology is appropriate for all ages, although for older women, instruments that allow sampling of endocervical cells are recommended.

#### **Screening frequency**

As noted, cervical cancer generally develops slowly from precursor lesions. Therefore, screening can take place relatively infrequently and still have a significant impact on reducing cervical cancer morbidity and mortality. Based on the ACCP's mathematical modeling studies using observed data (prospective cohort studies, databases, and published literature), if resources permit only once-perlifetime screening, then the focus should be to screen women in the 30s and 40s, especially women between 35 and 40 years. If resources allow screening two or three times per lifetime (rescreening), the optimal interval should be every five years (not every ten years); for example, screening at ages 35, 40, and 45 is better than screening at ages 30, 40, and 50 (Goldhaber-Fiebert et al. 2003, Goldie and ACCP 2004, personal communication with S. Goldie, May 2004). If resources permit more frequent screening, however, then screening can be once every three years from age 25 to 49 and then every five years to the age of 64 (IARC forthcoming).

#### Screening coverage

Coverage refers to the extent of participation of eligible (i.e., target age) women in the screening program in a given time period and is calculated by dividing the number of eligible women screened during a given time by the total number of eligible women. High coverage of the target population is one of the most important components of a successful cervical cancer prevention program (Pretorius et al. 1991, Sasieni 1991, WHO 1992).

Evidence from some countries where screening programs are in place shows that more than 50% of women diagnosed with cervical cancer have never been screened (Sung et al. 2000). Since most cervical cancer occurs in unscreened women, reaching them with prevention services will have the greatest impact in reducing the incidence of and mortality from cervical cancer. Unnecessarily rescreening women and routinely screening those outside the target age group (e.g., 20-year-old

women attending clinics for prenatal care) can result in substantially higher costs with minimal population benefits. Increasing coverage is generally more important than marginal increases in the frequency of screening (Miller 1992, Sasieni 1991)—or even small increases in the sensitivity of the screening test (Kim et al. 2002a, Kim et al. 2002b)—particularly for countries with low screening coverage (e.g., below 25%). Based on this evidence, the program's coverage objectives should be to focus on screening women in the target age group and to avoid repeatedly screening women who have already been screened in the recent time period.

Once coverage goals are set, the management team must apply them to the population in their own catchment area. This is addressed in Chapter 5. If national coverage goals have not been set, a key step in program planning would be to set such goals for the local area.

#### Maximizing access to health care providers

The ACCP has found that a wide range of competently trained medical personnel, both physicians and non-physicians, can provide cervical cancer screening and treatment. The decision regarding who can perform specific procedures should be based on national norms and regulations. If norms and guidelines are unnecessarily restrictive, decisions should be made jointly with the relevant in-country professional organizations or licensing bodies to revise the norms and guidelines.

#### **Vertical versus integrated programs**

In vertical programs, health care providers and facilities are devoted to only one health care service. A fully integrated program involves integration of all aspects of programming: planning and budgeting, organizational structure, staff roles and responsibilities, training, supervision, logistics, information systems, monitoring, and clients' access to services (Management Sciences for Health 1994). In integrated programs, clients can access more than one health service at the same facility, on the same day, and (sometimes) from the same health care provider. Many factors influence the decision on whether to integrate cervical cancer prevention programs with other health programs. They include political commitment to integration in the existing health structure, competing health priorities, existing national policy on cervical cancer prevention, availability of personnel and material resources, requirements for a shift in resources, and donor preferences and commitment of resources.

Management teams need to consider the strengths and limitations of integrated and vertical programs (see Table 2.1). Ideally, to maximize client access, programs should work toward providing integrated services to the degree that the resources and capacity allow. It is important, however, to ensure that integrated services do not result in an excessive workload for providers, which can adversely affect service delivery and the program's effectiveness. Integrating cervical screening services will work only when services are able to reach a large group of women aged 30 and older. For example, integrating cervical cancer prevention with family planning services makes cervical cancer prevention services less likely to reach older women, because 50% to 60% of women attending family planning clinics are younger than 30 years old (Claeys et al. 2003). Regardless of whether the program is vertical or

integrated, it is important to have a holistic approach to a client's needs and to ensure she receives or is referred for all the services she needs to ensure her good health. Further discussion of vertical and integrated services is found in Chapter 6.

**TABLE 2.1.** Strengths and limitations of vertical and integrated programs

	Vertical Program	Integrated Program
Strengths	<ul> <li>Higher commitment to and focus on the cervical cancer prevention objectives.</li> <li>Staff roles and responsibilities are clearly defined.</li> </ul>	<ul> <li>Health benefits from the opportunity to deal with several health problems during the one visit.</li> <li>Avoids stigma that a "cervical cancer service" might generate.</li> <li>Can use an existing referral network, plus benefit from on-site referrals.</li> <li>Wider range of staff available.</li> </ul>
Limitations	<ul> <li>Higher cost for the health system (since facilities and equipment are not shared).</li> <li>Logistical and cost burden to the client (cost of transport, work, and family responsibilities) for referrals or if she needs other health services.</li> </ul>	<ul> <li>Competing priorities (prevention seen as less urgent than treatment).</li> <li>Higher level of planning and organization required.</li> <li>Has the potential to excessively increase the providers' workload.</li> <li>Providers' and supervisors' roles and responsibilities are less well defined.</li> </ul>

#### **Conclusion**

The policy phase of program development is critical because it assesses needs at a population or country level, determines policies that will guide service delivery, and develops political and financial support for programming. The policy phase should be as participatory as possible, involving key national stakeholders and clearly basing policy decisions on the needs and health priorities of the population. Understanding the factors involved in policymaking will help the management team to explain the rationale for program policies and build support at the local level for program planning and implementation.

Given the necessity to commit resources for whatever strategy is chosen, cost-effectiveness becomes a critical consideration for policymaking. Based on the available evidence from cost-effectiveness analysis (Goldie et al. 2001, Mandelblatt et al. 2002), it is recommended that cervical cancer screening policy in limited-resource settings should:

- Focus initially on screening women who are in their 30s and 40s.
- Focus on a screening and treatment approach that involves a reduced number of visits (to minimize the loss to follow-up that occurs with each additional visit).
- Focus on high coverage over increasing screening frequency.

#### **Further Reading**

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Two

# Planning and Managing a Program

Part Two of this manual provides information on how to systematically plan and manage a cervical cancer prevention and control program. The processes described can be used to design a new program or to strengthen an existing program, and can be adapted to reflect local situations and circumstances.

**Chapter 3** provides information on the organization and role of a team to plan an effective cervical cancer prevention program. It also describes the essential components of a program, introduces the principle of quality of care, and gives details on the first step in planning.

**Chapter 4** describes the second step of program development—needs assessment—with sample interview questions provided in an appendix.

**Chapter 5** considers the remaining steps of program development: creating a program action plan, determining budget allocations, and setting up systems for service delivery and quality management prior to launching a program.

# **Initiating the Planning Process**

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#### **Key Messages**

- The national cervical cancer prevention and control program coordinator establishes a multidisciplinary management team, and together they plan, implement, and evaluate the program.
- A cervical cancer prevention and control program consists of three service delivery components that must be linked together: community information and education (I&E), screening services, and diagnostic and/or treatment services. Critical to the effectiveness of these components are training, monitoring and evaluation, and policy.
- Engaging key stakeholders is crucial before starting program planning and implementation.
- Defining and ensuring good-quality work processes and systems at all levels is the responsibility of the management team with assistance from the stakeholder advisory group and task groups.

#### Introduction

Systematic planning and investments in health services are required for a well-managed cervical cancer prevention and control program. In many countries, however, it has been observed that there is little accountability, planning, or attention given to programmatic structure and management, rendering screening and treatment services less effective than they could be.

As described in the previous chapter, planning and implementing the program is preceded by a national-level policy phase. This phase establishes the foundation for programming and includes designating a program coordinator. Before moving from the policy phase to planning the program, the coordinator should establish a management team, and together they should engage local stakeholders. Figure 3.1 illustrates the various steps in the program planning and implementation process and how they relate to the policy phase.

FIGURE 3.1. The policy and program management process

Confirm political commitment, invest resources, and designate a coordinator for a new or strengthened program. Engage high-level stakeholders. **Policy Phase Ministry of Health** Analyze existing situation to determine feasibility to create a Senior Health Advisors new or strengthened program. and Stakeholders Develop national policies, guidelines, and norms. Obtain support for new policies and resources for programming. Plan the program by engaging local stakeholders, assessing local needs, and developing a program action plan and budget. **Planning and Implementation** Phases Modify Build the capacity for the program program and prepare for implementation. based on evaluation Program Management Team results. Launch, implement, and monitor the program. Evaluate the program for outcomes.

The program coordinator must have the appropriate mandate, authority, and resources to direct the program with the multidisciplinary management team. The team should lead the planning, implementation, and evaluation of the program. This would apply to the creation of a new program or to the strengthening of an existing program. Depending on the country's health system, a management team would function at a national or subnational level.

The principal roles of the management team are to:

- Involve local stakeholders in the planning and implementation of the program.
- Assess local needs for the program.
- Develop a program plan and budget.
- Provide overall management, budgetary, and evaluation support during program implementation.
- Coordinate activities between the various program components.

Members of the management team should possess the skills and expertise needed to carry out the principal roles. Sharing responsibilities will be necessary among all

members of the team, as will tapping the experience and perspectives of stakeholders and community members. Forming small task groups for specific components of the program plan and its implementation is one good strategy for ensuring that the expertise of team members is strategically leveraged. For example, a task group may be established to oversee a local needs assessment or to oversee the development of an information system, and the task



Management teams play an essential role in program planning, implementation, and evaluation.

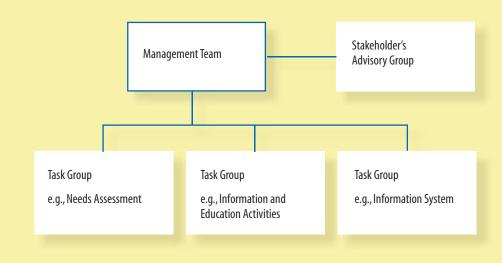
group could report back to the management team on its recommendations. One model for how a management team may operate is provided in the next box.

#### A Management Team for a Cervical Cancer Prevention and Control Program

A management team, headed by a program coordinator, could be composed of individuals with varying skills and competencies, such as:

- Health administration and management.
- Public health, data collection, and analysis.
- Medical and clinical skills such as nursing, general medicine, gynecology, oncology, and pathology.
- Laboratory management.
- Community health education, social sciences.
- Training.
- Logistics and supplies management.

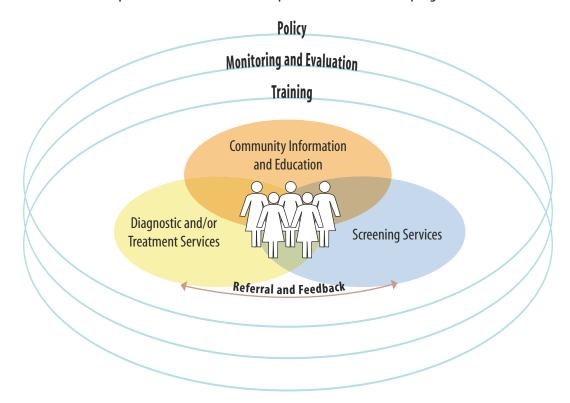
A stakeholder advisory group can support the management team in program planning and ensuring quality during implementation.



#### **Components of the Program**

The success of a program depends not only on the screening and treatment methods, but also on the resources and requirements necessary to deliver screening and treatment to a large group of women who need these services, as well as the willingness and ability of the women to avail themselves of these services. When planning a new or strengthened cervical cancer prevention program, the management team will need to consider all the necessary components of such a program. As illustrated in Figure 3.2, women's needs and concerns should be at the center of program planning and implementation. The three main service delivery components that must be linked together—community I&E, screening services, and diagnosis and/or treatment services—are encompassed by three elements that are critical to program success and quality of care: training, monitoring and evaluation, and policy.

**FIGURE 3.2.** Components of a cervical cancer prevention and control program



#### **Service delivery components**

#### **Community information and education**

These activities are necessary to inform and educate women and men in communities about cervical cancer both to encourage and support women to participate in screening services and to ensure the program reaches its coverage goals. These activities should be implemented in communities, health facilities, and through various media. Linkages must be established between the community and the health facilities.

#### **Screening services**

Screening services, including counseling before and after screening, must be available and accessible. All clients must be informed of their test results, and there should be efficient tracking systems for all clients who need rescreening or referral for diagnosis and/or treatment. Where cytology or HPV DNA tests are used, laboratories must have the capacity to process the samples with minimal delays, use uniform reporting terminology, and have appropriate mechanisms to optimize the quality of test results. Linkages must be established and maintained through referral and feedback (counter-referral) between laboratories and the health facilities and between the various levels of health services.

#### Diagnosis and/or treatment services (precancer and cancer)

Cervical cancer screening services must be linked to accessible treatment for women with precancerous cervical lesions. Where prevention strategies include diagnostic and confirmatory steps, colposcopy and biopsy services must be available, with links between screening and diagnostic services to histopathology laboratories. In general, colposcopy and biopsy services should be available to evaluate suspected invasive lesions. Cancer management services, including surgery (or, at the very least, palliative care), should be available for women with invasive cancer. Information and counseling should be integral parts of all treatment services.

In each of these components, the availability of trained staff, functioning equipment, and supplies is necessary for effective program implementation. Links between each component are necessary to ensure appropriate client management and continuity of care.

#### Three critical activities for program success

The service delivery components are supported by three activities that are essential for both establishing and sustaining quality services.

#### **Policymaking**

Policies provide the foundation and guidelines for all aspects of the program and delivery of services. They are usually developed at the national or subnational level and involve several essential steps (as discussed in Chapter 2). Key policy decisions that drive the program include the screening and treatment methods, target age group for screening, frequency of screening, the desired population coverage, the regulations permitting mid-level health providers to perform clinical procedures, and whether the program will be vertical or integrated into other health services.

#### **Training**

Training requirements are driven by reproductive health policies. Training itself is usually implemented via the institutions and structures that routinely train health workers, and it requires a commitment of resources to be sustainable. All staff involved in each component should be trained and competent in their particular roles. The knowledge, attitudes, and skills necessary to carry out their roles should be determined, and training provided or reinforced, as necessary, to ensure that the members of each staff are able to perform their roles to standard norms. This applies to outreach workers providing community I&E; to non-medical support staff at the clinic; to medical staff providing screening, diagnosis, and treatment services; to staff assigned to data collection and analysis; and to the supervisors who are responsible for ensuring performance quality.

#### Monitoring and evaluation

Monitoring and evaluation involves defining goals based on national policy, conducting ongoing activities to ensure that quality services are provided to enable reaching these goals, collecting and analyzing data related to these goals, and taking timely corrective action to uphold quality of care and program performance. Monitoring and evaluation should cover all service components, including laboratory service.

#### **Quality of Care: Addressing Clients' Rights and Providers' Needs**

A quality focus in all areas of service provision is important, since the quality of the services will influence the program outcomes. Therefore, attention must be given to ensuring quality in service delivery during the planning, implementation, and evaluation of the program. Two overarching principles of quality assurance are supporting clients' rights and addressing providers' needs. For quality services, providers need to be able to meet the clients' rights by offering:

- Complete and accurate information.
- Access to services.
- Informed decision-making.
- Safety of services.
- Privacy and confidentiality.
- Dignity, comfort, and expression of opinion.
- Continuity of care.

The program will need to have the systems and capacity in place to support the work of the providers, which include:

- Good quality management and supervisory support at the facility and district levels.
- Information, training, and skills development.
- Adequate supplies, equipment, and infrastructure.

Sources: EngenderHealth 2004, Huezo and Carignan 1997.

#### **Engaging Stakeholders**

The first step in developing a program involves engaging stakeholders to participate in the planning and management of the program. Stakeholders' involvement and sense of ownership are critical for the successful implementation of the cervical cancer prevention program. To make certain that programs address women's needs and concerns, special efforts should be made to involve women in developing, implementing, and evaluating program interventions and informational messages.

Table 3.2 suggests some of the recommended stakeholders. The management team should identify the individual stakeholders in their community and invite them to be involved in various aspects of program planning or implementation. Stakeholders could be invited to serve on a stakeholder advisory group or task group, or they could be invited to provide advice for specific activities, such as the design of educational materials.

**TABLE 3.2.** Recommended stakeholders to involve in planning and implementing a cervical cancer prevention and control program

Program components	Recommended stakeholders
Community information and education activities	<ul> <li>Health facility managers.</li> <li>Clinic supervisors/area managers.</li> <li>Health promotion staff.</li> <li>Community-based NGO representatives.</li> <li>Community members.</li> </ul>
Screening services	<ul> <li>MOH officials.</li> <li>District administrators.</li> <li>Health facility managers.</li> <li>Clinic supervisors/area managers.</li> <li>Laboratory personnel (e.g., pathologist, cytotechnician).</li> <li>Representatives of medical, nursing, and allied health professions.</li> <li>Procurement and supplies staff.</li> <li>Purchasers (e.g., health insurance organizations).</li> <li>Community members.</li> </ul>
Diagnosis and treatment services: precancer and cancer	<ul> <li>Same as above and in addition:</li> <li>Colposcopy center managers.</li> <li>Treatment facility managers.</li> <li>Clinicians (e.g., gynecologists/gynecological oncologists/radiotherapists).</li> <li>Laboratory personnel.</li> </ul>
Training	<ul> <li>Health facility managers.</li> <li>Trainers and human resource officials.</li> <li>Representatives of medical colleges.</li> <li>Representatives of medical, nursing, and allied health professions.</li> <li>Clinic supervisors/area managers.</li> <li>Laboratory personnel.</li> <li>Staff representatives (doctors and nurses).</li> <li>Maintenance staff.</li> </ul>
Monitoring and evaluation	<ul> <li>District/regional/provincial information system officers.</li> <li>Clinic supervisors/area managers.</li> <li>Health facility managers.</li> <li>Laboratory managers and cytopathologists/ cytotechnologists.</li> <li>Colposcopy and treatment facility managers and clinicians.</li> <li>Researchers.</li> <li>Health economists.</li> <li>Community members.</li> </ul>

Source: Adapted from Cervical Health Information Project (CHIP) 2004a.

An advisory group, comprising key stakeholders at the national or subnational level, can be a useful way to support the management team in program planning and ensuring quality during implementation (CHIP 2004a). In places where health advisory committees already exist, it would be useful to suggest including cervical cancer prevention and control as a topic on their agenda. If a suitable health committee does not exist, a new committee could be formed, ideally consisting of 10 to 15 members, to advise the management team and assist in overseeing program implementation and monitoring and evaluation.

#### **Conclusion**

Program planning should be based on the policy decisions, taking into consideration all the components of the program and focusing on providing quality services. The designated program coordinator working together with a multidisciplinary management team and task groups is accountable for directing the program from planning through implementation, paying particular attention to quality of care issues. The management team should identify individual stakeholders in the community whose participation in advisory and task groups is crucial to the success of program planning.

#### **Further Reading**

EngenderHealth. Facilitative Supervision Handbook. New York: EngenderHealth; 2001.

PATH. *Planning Appropriate Cervical Cancer Prevention Programs*. 2nd ed. Seattle: PATH; 2000.

World Health Organization (WHO). *National Cancer Control: Programmes, Policies, and Managerial Guidelines*. 2nd ed. Geneva: WHO; 2002[a].

## Appendix 3.1. Checklist for Planning and Implementing a Program

Policy		
	Con	firm political commitment.
		Invest necessary resources.
		Designate program coordinator with mandate, authority, and resources to direct the program.
	Eng	age high-level stakeholders.
	Con	duct situation analysis.
	Dev	elop/review policies, guidelines, and norms.
		Evaluate screening and treatment methods and approaches.
		Establish target age group for screening.
		Determine frequency of screening.
		Determine desired population coverage.
		Establish regulations authorizing mid-level providers to perform screening and treatment.
		Determine whether program will be vertical or integrated.
	Com	nmit/solicit resource and obtain support for the new policies.
Planni	na t	he program
		ıblish a management team.
		age local stakeholders.
	_	ess local needs.
		elop the program action plan.
		Determine local screening coverage goals.
		Establish estimates for treatment caseload.
		Review service delivery strategies.
		Develop training plan for providers.
		Information and education strategies
	_	ŭ
П		elop the budget and allocate resources according to the program on plan.

### Preparing to launch the program

	Esta	blish systems for service delivery.
		Develop program materials.
		Provide orientation for community, stakeholders, and staff.
		Ensure provider training and availability.
		Procure and distribute equipment and supplies.
	Esta	blish systems for quality management.
		Build capacity to ensure quality.
		Set up the system for supervision.
		Define the quality indicators.
		Set up the information system.
	Lau	nch the program with an inaugural event.
Impler	nent	tation
		Provide community information and education to address community and client needs.
		Deliver clinical services and ensure linkages between services.
		Ensure performance to standards of trained providers.
		Monitor and supervise the work of providers to ensure quality of care.
		Monitor and evaluate the program performance and outcomes.
		Modify the program based on monitoring and evaluation results.

# **Assessing Program Needs**

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#### **Key Messages**

- A local needs assessment enables the management team to identify
  what inputs are required to achieve the objectives of a cervical cancer
  prevention and control program.
- The assessment is best conducted through a participatory process involving a multidisciplinary team of stakeholders.
- The categories to be assessed include adherence to program policies, guidelines, and norms; program management issues; health services; information and education (I&E) activities; the community perspective; laboratories; infrastructure, equipment, and supplies; and information systems.
- It is important to obtain the perspectives both of the people involved in providing and those involved in receiving services for cervical cancer prevention.

#### Introduction

A needs assessment is a process of gathering necessary and relevant information from which informed decisions can be made about planning a new or strengthened cervical cancer prevention program. It is generally the second step in a program planning cycle (the first being to engage stakeholders) and is completed prior to developing or strengthening the program. The assessment involves the development of strategic questions, followed by the systematic collection and analysis of information. The purpose is to understand the perspectives of people involved in providing or receiving services and identify gaps in services. This chapter provides guidance on how to conduct a local needs assessment as a step in developing or improving a program.

#### What Needs to Be Assessed?

The areas that should be assessed are described below. The assessment team should first define the overall strategic questions that are to be answered by the needs assessment (e.g., what is needed in order to screen all women in the target age group?). This will help the team to determine in which areas to focus the needs assessment and what specific questions need to be answered. Sample questions, which would be adapted by the assessment team to fit the local situation, are provided in Appendices 4.1 to 4.7. As part of the background preparation, the assessment team members should familiarize themselves with demographic information, the cervical cancer situation in their country, and the structure of health services

Where there are no systems or structures in place for providing cervical cancer prevention services, the focus should be on assessing capacities described in this chapter with respect to launching new services. Obtaining feedback from key stakeholders in each area is essential to inform strategic decisions on how to effectively launch and sustain new prevention efforts.

#### Program policies, guidelines, and norms

The consistent use of existing program policies, guidelines, and norms at the local level is important for achieving a standard of care. The policies that govern the program and delivery of services, the clinical practice guidelines for screening and treatment of precancerous lesions, and the treatment guidelines for cervical cancer all clarify health care providers' understanding of their professional responsibilities. As such, the assessment team should determine the extent to which health professionals are aware of the existence of the policies and guidelines, their perceptions of these policies and guidelines, and the extent to which they follow them in their practice. This information can be gathered by interviewing administrators and health professionals from local health institutions. Appendix 4.1 contains suggested questions for interviewing administrators and health professionals.

#### **Program management issues**

A needs assessment must consider program management aspects in order to:

- Understand how services for cervical cancer screening and treatment currently are, or could potentially be, organized and delivered.
- Identify the key organizations involved in delivering these services, including potential leaders, coordinators, or area supervisors.
- Define the level of available resources and assess how services could be financed.
- Document the system for requesting and purchasing equipment and supplies, and for improving infrastructure.

Information can be collected by interviewing key authorities in the Ministry of Health (regionally and locally); those health professionals responsible for the reproductive health program, cancer control program, or chronic disease program; presidents and program managers from cancer institutes, cancer leagues, cancer societies, and other nongovernmental organizations involved in cancer prevention; and members of medical associations, pathology associations, gynecologic associations, oncology groups, and other professional bodies. Appendix 4.2 contains sample questions.

#### **Health services**

The needs assessment should involve a thorough review of the local health services at the primary, secondary, and tertiary level of care within the chosen area of study (e.g., health region or municipality) to determine:

- Type and scope of services currently available.
- Access to health services in terms of physical access, facility conditions, and timeliness of receiving appointments and test results.
- Coverage of women at risk, including the age group currently being served by screening activities, and what barriers exist to achieving high coverage.

- Client-tracking and referral mechanisms for providing test results (if applicable), for treatment, and for follow-up care, including existing linkages between the levels of care for screening, diagnosis, and treatment.
- Acceptability of introducing new screening and treament approaches such as cryotherapy treatment delivered by mid-level providers.
- Human resources and capacity, including screening and treatment services, outreach and client recruitment, counseling, and health information system (HIS) maintenance.
- Infection control and instrument processing, including standards and practices currently in place.
- Availability and quality of supervision and monitoring, including who currently coordinates those systems.
- Linkages between services and health sectors.

The health services system can be assessed by interviewing health care providers and administrators. In addition, the services themselves should be assessed by visiting and making observations of the conditions and operations. Appendix 4.3 contains sample questions for interviews with health personnel on issues related to the health services for cervical cancer screening and treatment.

#### Information and education activities

The methods and materials used to inform, educate, and meet women's informational needs for cervical cancer prevention are important for ensuring that women take up screening services as well as return for follow-up care. The needs assessment must therefore consider the I&E strategies that are used or could be used to reach women in the community and in the health facilities.

Aspects that may be considered include strategies to communicate information, both in clinics and in the community; availability of information materials; type and purpose of information materials; accuracy, consistency, and relevance of messages; methods used to develop and test I&E materials; and methods to train health providers and community health workers (CHWs) to use the materials. Appendix 4.4 contains a list of sample questions.

#### **Community perspectives**

It is important to consider the perspectives of women and men in the community, their knowledge about cervical cancer, and their service needs in order to develop services that will meet their needs. Furthermore, these perspectives are important for developing promotional campaigns that address their knowledge gaps and concerns. Potential clients and their husbands (or partners) can be surveyed by CHWs or other health outreach staff who normally interact with community members. Aspects to be considered include understanding of the concept of preventing disease, knowledge of cervical cancer, awareness of cervical cancer prevention services, feelings about screening, possible barriers to utilizing screening services, and attitudes toward the health care system. Appendix 4.5 lists some sample questions.

#### **Laboratories**

Laboratories that manage (or could manage) cytology, HPV DNA testing, or histopathology should be assessed. The objective of assessing laboratories is to evaluate their capacity, performance, workload, and needs against a generally accepted standard. It is also important to assess the availability and effectiveness of audit protocols and systems for continuing professional development. A pathologist with experience in cytology should be involved in the assessment of the laboratories and should visit and interview cytopathology laboratory directors, pathologists, technicians, and other key personnel. The assessment should include observations and documentation of the following aspects of services:

- The laboratory procedures and processes including the flow of information.
- The physical environment, the infrastructure, equipment, supplies, and storage capacity in the laboratory.
- Availability of essential equipment and supplies needed to process the tests.
- The time required from receipt of tests to sending test results back to the testing site.
- Qualifications and number of technical staff available to process tests
- Procedures for processing tests.
- Quality control methods used within the laboratory and external to the laboratory.
- The current and potential volume of tests processed, quality of the tests received, and the quality of the test results.
- The mechanisms and effectiveness of linkages for communicating results from the laboratory to the health facilities.

Appendix 4.6 contains sample questions for assessing a laboratory.

#### Infrastructure, equipment, and supplies

The needs assessment should document the availability, accessibility, and adequacy of functioning equipment and supplies needed for screening and treatment services. In addition, information should be gathered on the requisition, purchasing, and distribution as well as repair and maintenance procedures for infrastructure and equipment in order to identify how these procedures may be improved. Information for this part of the needs assessment can be obtained through observations in the health centers and clinics and through interviews with clinicians and health administrators. For a list of equipment and supplies recommended for a cervical cancer prevention and control program, refer to Appendix 6.1.

#### **Information systems**

A cervical cancer prevention and control program requires good records, whether paper-based or computerized, to monitor the management of women in the program as well as to evaluate the program against set indicators or benchmarks. Ideally, the system should identify the number of women in the target population, record personal and clinical information on women screened, and generate lists of women with positive test results who need follow-up care.

The information system could then be used to evaluate screening coverage, test quality, and the completeness of follow-up care. At a minimum, the system should collect information at the local health care site using client forms or registers. This information should then flow to referral health care sites or laboratories (if applicable) and to a centrally located program coordinator, who monitors women's test results and the program's coverage goals.

Therefore, the needs assessment should identify the current manner in which screening and treatment information is collected, recorded, analyzed, and monitored for clinical and program evaluation purposes. This activity should include determining whether this information is integrated into a national HIS or is managed separately. The assessment should note data sources, assess the forms used to record clinical and administrative information, describe the flow of forms/information, and, if applicable, evaluate any electronic HIS being used. The assessment should include reviewing current forms and interviewing program managers, health administrators, laboratory personnel, and clinicians. Appendix 4.7 contains sample questions.

#### **How to Conduct the Local Needs Assessment**

The needs assessment should be a participatory process with three phases: a preassessment phase where all the preparatory work is completed, an assessment phase where new information is gathered and analyzed, and a post-assessment phase where the report is written, findings are presented to health authorities, and plans are made to implement actions that will introduce or improve screening and treatment services.

#### **Pre-assessment phase**

#### **Involve local stakeholders**

Stakeholders should be informed about the needs assessment objectives and process. They should also be invited to participate as part of the assessment team or to attend meetings where the assessment results are presented and subsequent plans are made for service improvements.

#### Establish the assessment team

An assessment team—a task group of the management team—should be formed to conduct all the interviews, site visits, data collection, and analysis. The assessment team should include representatives and stakeholders from the region, both from the public and private health sector. It is important that the team has a good

mix of technical, administrative, and communication skills. Various disciplines should be represented in the group, such as nursing, general practice, epidemiology, gynecology, pathology, sociology, health promotion, public health, and a program manager from the Ministry of Health. It is important that the team members are interested in the project and will be able to devote time to do the needs assessment. A designated leader for the assessment should be selected based on his or her leadership skills and abilities.

The assessment team's role is to:

- Define the strategic questions to be answered in the needs assessment.
- Assess the current state of cervical cancer prevention and control efforts within a geographically defined area.
- Identify the needs and the conditions that assist or act as barriers to
  achieving the three goals of a program: coverage of women, quality
  screening test, and appropriate treatment for all screen-positive
  women.
- Identify the specific actions and resources required for an organized screening and treatment program.

#### Orient the team

A workshop should be held with all team members to orient them to the assessment objectives, to ensure a common understanding of the technical issues related to cervical cancer prevention and conducting an assessment, to discuss and plan the methodology, to design the interview tools, and to plan all aspects of the process. The workshop is also useful to build teamwork and cooperation among members.

#### **Define the methodology**

The assessment team will review the methodological options for collecting quantitative and qualitative information and the actual methods to be used (see Table 4.1), based on the decisions regarding the scope and extent of the needs assessment. Methodological options include focus group discussions, individual interviews, mailed questionnaires, review and analysis of randomly selected clinical records within the preceding 6 to 12 months, and visiting facilities that provide services. The team will define whom to interview and select the sample of interviewees and health facilities from all levels of the health system in all the coverage areas. Sample questions are provided in Appendices 4.1 to 4.7.

**TABLE 4.1.** Methods to collect information for the needs assessment

Areas to assess	Collection method
Policies, guidelines, and norms	Review documents.
	Interview health administrators and health care personnel.
Program management issues	Interview health administrators and health care personnel.
Health services	Interview health care personnel.
	Observations in health centers.
	Review clinical records.
I&E activities	Interview health care personnel and community
	health workers.
Community perspectives	Focus groups with clients/community members.
	Interview clients.
	Survey community.
Laboratories	Interview laboratory personnel.
	Observations in laboratories.
Infrastructure, equipment, and	Interview health administrators and health providers.
supplies	Observations in health centers and clinics.
Information systems	Interview health administrators.
	Review documents.

#### **Schedule site visits**

Depending on the scope of the assessment, the team should make necessary transportation and accommodation arrangements, as well as schedule all site visits and interviews in advance. This will involve communicating and coordinating visits with health authorities and with staff at the facilities. If services are performed on specific days, efforts should be made to schedule visits accordingly. It is important to inform staff at the facilities about the need to observe procedures and the purpose of the visit, reinforcing that the visit is not to evaluate their work but to discuss their needs. It is also important to inform staff at the facility being visited that information they provide will be reported without a personal attribution. The facilities that should be visited include public-sector facilities (primary, secondary, and tertiary); private-sector facilities; facilities in urban, peri-urban and rural areas (as applicable); facilities providing or having the potential to provide services for screening and treatment of precancer; laboratories (cytopathology, HPV DNA labs); and cancer management centers such as units providing radical surgery, radiotherapy, oncology, and palliative care units.

#### **Assessment phase**

#### **Collect information**

The assessment team should collect information as per the methodology chosen. Depending on the size of the assessment team, it may be more efficient to break into several smaller teams to collect information over a larger geographic area and subsequently pool the information. The assessment team should identify the main interviewer(s), who are selected based on their skills and abilities to conduct interviews in a conversational and nonthreatening manner. Where possible the team should collect samples of printed material (e.g., information leaflets used) and data (e.g., clinic service data). A person should be designated to record all the findings from the site visits and interviews, using handwritten notes, tape-recorded interviews (if feasible), and photographs (where possible and if permitted by the concerned people).

#### **Review data**

At the end of each day of data collection and interviews, the assessment team must debrief and begin to identify the key points, recurring themes, and issues emerging on the challenges and needs of an organized cervical cancer prevention and control program. During this daily debriefing any outstanding questions or missing information can be identified in order to mark key information that needs to be gathered during the following day's interviews.

#### Analyze data and make recommendations

Once all the information has been collected, the assessment team should collate, synthesize, and analyze the information. This stage should be done in a group where all members can discuss the key points that emerged during the data collection phase and analyze any common themes or obvious gaps in the current cervical cancer prevention program. The team will analyze the information following the categories outlined in the previous section (What Needs to be Assessed), including new issues that arise during the course of conducting the needs assessment. Based on the findings and conclusions of the needs assessment, the team develops appropriate recommendations.

#### Post-assessment phase

#### Write the report

A member of the assessment team should be designated as a writer, who in consultation with all assessment team members prepares the report documenting the methodology and findings. The designated writer should be selected based on her or his skills and abilities to write clearly and concisely and must collaborate with other members to agree on the presentation of findings. The report should be brief, with data to support findings wherever possible. The report should be completed in a timely manner.

#### Present and disseminate the report to stakeholders

During meetings with key stakeholders, the assessment team presents their findings and conclusions, creates support for developing or strengthening a cervical cancer prevention program, and develops the plan for the program. The report should be disseminated to relevant stakeholders in a timely manner.

### Develop a program plan

Once the stakeholders and authorities have reviewed the findings and accepted the recommendations, a program plan needs to be developed that delineates the activities, responsible organizations, and resources required to implement the recommendations. Ideally the plan should be developed by the management team, in collaboration with the assessment team. The plan may require formal approval and acceptance by the stakeholders and organizations responsible for delivering services (e.g., Ministry of Health or private-sector health service managers). Chapter 5 describes how to develop the program plan and a budget.

## **Conclusion**

The second step in a program planning cycle (the first being to engage stakeholders) is for a multidisciplinary assessment team (task group) to collect and analyze information on local needs and availability of resources. Recommendations from this local assessment should be used to develop an action plan to implement a new program or to strengthen an existing program.

## **Further Reading**

EngenderHealth. COPE® for Cervical Cancer Prevention Services: A Toolbook to Accompany the COPE® Handbook. New York: EngenderHealth; 2004.

JHPIEGO. Cervical Cancer Assessment Checklist. Baltimore: JHPIEGO; 1999.

Pan American Health Organization (PAHO). A Needs Assessment Guide for a Cervical Cancer Prevention and Control Program. Washington, D.C.: PAHO; 2002[a].

PATH. Program Capacity Assessment Tool: Integrating Cervical Cancer Prevention Into Reproductive Health Services. Seattle: PATH; 2001. Reproductive Health Reports, No. 4.

## Appendix 4.1. Sample Questions to Assess the Use of Policies, Guidelines, and Norms

This is a list of sample questions for interviewing health administrators and health professionals to understand their awareness and use of policies, guidelines, and norms related to cervical cancer prevention and control. These questions could be adapted and modified to suit the specific situation concerning the policies, guidelines, and health situation in your country.

- 1. Are you familiar with the reproductive health program that includes cervical cancer prevention? Are you aware of a national cancer control program which includes cervical cancer prevention?
- 2. In your opinion, how does cervical cancer prevention rank as a program priority within the health services?
- 3. In your opinion, what are the competing health priorities in this region/ area for cervical cancer prevention?
- 4. Are there assigned resources dedicated to cervical cancer prevention within the health authority's budget? If so, are these resources adequate for the current level of programming?
- 5. Are you aware of the policies that govern the type of screening, diagnosis, and treatment that is offered in the country?
- 6. What are the policies that govern the following aspects of cervical cancer prevention and control?
  - a) Screening tests.
  - b) Diagnostic tests.
  - c) Treatment options for precancerous lesions.
  - d) Treatment for cervical cancer.
- 7. Are there clinical practice guidelines (written or unwritten practice norms) for cervical cancer screening and treatment services?
- 8. What do the clinical practice guidelines state for the following areas:
  - a) Age to initiate screening.
  - b) Target age group for screening efforts.
  - c) Coverage goals.
  - d) Screening interval.
  - e) Screening tests to use.
  - f) Standard terminology for reporting screening results.
  - g) Health professionals permitted to conduct the screening test and/or treatment for precancerous lesions.
  - h) Methods to manage women with positive screening test results.
- 9. Do you accept the guidelines and use them in your practice?
- 10. Are there guidelines or laws that regulate opioid availability for palliative care services?
- 11. Overall what are the strengths and weaknesses of the policies and guidelines for cervical cancer prevention?
- 12. In your opinion how can the weaknesses be improved?

## **Appendix 4.2. Sample Questions to Assess Program Management Issues**

This is a sample list of questions for interviewing local key authorities in the Ministry of Health; those responsible for the reproductive health program, cancer control program, or chronic disease program; presidents and program managers from cancer institutes, cancer leagues, cancer societies, and other NGOs involved in cancer prevention; and members of medical associations, pathology associations, gynecologic associations, and oncology groups. These questions could be adapted and modified to suit the specific situation concerning the health care infrastructure, health priorities, and programs in your country.

- 1. Is there a program for cervical cancer prevention and control with defined goals, targets, and objectives? If no, could an organized program be developed?
- 2. Is there a national policy for cervical cancer screening and treatment? What is contained in the national policy about screening target age group and coverage targets?
- 3. How is or could the program be structured in terms of its management and delivery of services at the primary, secondary, and tertiary level of care?
- 4. Who is or could be responsible for leading and coordinating a cervical cancer prevention program?
- 5. Who is or could be responsible for serving as facility or area supervisor to monitor the implementation of the program in the health facility.
- 6. Approximately, what is the current screening coverage (percentage of women in the target population screened within the recommended interval)? Of the women screened, approximately what percentage of women received follow-up diagnosis/treatment?
- 7. Is there a functioning system to track women who require follow-up care and to reduce the number of women lost to follow-up?
- 8. Are women required to pay (totally or partially) for their screening test? For diagnosis (colposcopy and biopsy)? For treatment of precancerous lesions? For treatment of cervical cancer? If yes, what is the average cost to the woman for each service?
- 9. What are the indicators that are used, or could be used, to measure the program's success? How can the program's success be evaluated?
- 10. Overall, what are the strengths and weaknesses of the management of the cervical cancer prevention program? How can the weaknesses be improved?

## **Appendix 4.3. Sample Questions to Assess Health Services**

These sample questions are for interviews with health care providers on issues related to the health services for cervical cancer screening, diagnosis, and treatment. These questions could be adapted and modified to suit the specific situation concerning the health care infrastructure, health priorities, and programs in your country.

## Screening

- How are the screening services delivered: as part of the routine preventive health services for women; as part of maternal and child health services; as a special campaign for cervical cancer prevention?
   Other?
- 2. What strategies are used to identify eligible women and to recruit these women for screening services? How can these strategies be improved?
- 3. Where are the screening tests performed: community health post, health center, doctor's office, screening clinics, family planning clinics? Include the number of facilities and the number of tests performed per year.
- 4. Who performs the screening tests in the health clinic: general practitioner, nurse, other? What is the total number and type of health professionals providing the screening services?
- 5. Is special training offered to the health professional for performing the screening test? Are refresher training courses offered? If so, how often?
- 6. How is quality of care ensured for the women during the gynecological exam? How can this be improved?
- 7. With cytology, where are the screening tests analyzed and interpreted? Include the location and number of tests interpreted per year.
- 8. With cytology, what is the average length of time from when the screening test is done to when results are provided to the woman?
- 9. How are women notified of their screening test results? Who communicates the results to the woman? How well does this function? Is there counseling at the time results are provided? Is the woman given a copy of her results, or is it recorded in a client record card kept by the woman?
- 10. Is there sufficient equipment and supplies available in the health facility for screening services: gynecologic table, examination light, speculums, spatulas, slides, fixatives, clinic client forms, etc.?
- 11. Overall, what are the strengths and the weaknesses of the screening services? How can the weaknesses be improved?

### Diagnosis (if applicable)

- 12. What diagnostic tests are available to women with positive screening test results? How are women referred for diagnostic follow-up?
- 13. Are diagnostic tests used prior to treatment to verify screening test results? Where are the diagnostic services delivered? Who performs the diagnostic test?
- 14. What standard procedures are undertaken by the health facility to ensure that women are followed up with diagnosis and it is done as recommended? What percentage of women actually complete diagnosis?
- 15. How are women informed of their need for diagnostic follow-up? Is counseling provided to women at the time of their diagnosis?
- 16. On average, what is the length of time from when a woman is provided results from her screening test to the time of her diagnostic visit?
- 17. Overall, what are the strengths and the weaknesses of the diagnostic services? How can the weaknesses be improved?

#### **Treatment for Precancer and Cancer**

- 18. What treatment options are offered to women detected with precancerous lesions? With cervical cancer?
- 19. Where is the treatment delivered and who provides the service?
- 20. How is the woman informed of the need for treatment and the type of treatment she will receive? Is the woman provided with counseling at the time of treatment?
- 21. On average, what is the amount of time that elapses between when a woman is diagnosed with precancerous lesions and when she receives her treatment?
- 22. Is data available on treatment success/failure rates, complications, and women lost to treatment follow-up?
- 23. Overall, what are the strengths and the weaknesses of the treatment services? How can the weaknesses be improved?

## Appendix 4.4. Sample Questions to Assess Information and Education Activities

These are sample questions to be used for interviews with CHWs and health providers involved in delivering community I&E activities. These questions could be adapted and modified to suit the specific situation concerning the health care infrastructure, health priorities, and programs in your country.

- 1. Have there been studies to collect information on the knowledge, attitudes, and practices of women regarding cervical cancer screening and treatment? If so, what are the main findings?
- 2. Have there been studies to document the knowledge, attitudes, and practices of health care professionals regarding cervical cancer screening and treatment? If so, what are the main findings?
- 3. What public educational materials are available to inform women of cervical cancer prevention? How are materials/messages delivered to women? What are the main messages? What are the strengths and weaknesses of the materials? How can the weaknesses be improved?
- 4. What health education strategies are conducted in the community to encourage women to be screened and to be informed of their screening test results? How effective are these strategies? How can they be improved?
- 5. What health education strategies are undertaken in the health center to encourage at-risk women to be screened?
- 6. Are women themselves involved in communicating messages to their peers and educating women about cervical cancer screening? What evidence is there for the level and degree of peer communication in the community?
- 7. What institutions are or could be involved in community strategies to involve women and improve their participation in screening programs?
- 8. How are the information and education activities financed? What is the budget for these activities?

## **Appendix 4.5. Sample Questions to Assess Community Perspectives**

These are sample questions for interviews with women and men from the community regarding their knowledge, needs, and concerns related to cervical cancer. These questions could be adapted and modified to suit the specific situation and circumstances in your community.

## **Knowledge of cervical cancer**

- 1. What do you know about cancer?
- 2. What have you heard about cancer that affects the cervix/vagina/uterus/womb?
- 3. If nothing, what kind of sicknesses do you know of that can affect the woman in her reproductive organs?

## The concept of preventing disease

- 4. How do you avoid getting sick?
- 5. How do you protect your children from getting sick?
- 6. If you get sick, how do you avoid getting worse?
- 7. How do you think this concept of preventing disease could apply to cancer? To cervical cancer, in particular?

## **Awareness of cervical cancer prevention services**

- 8. What have you heard about cervical cancer prevention/screening/testing services in your area?
- 9. Do you know where to access these services?
- 10. Do you know from whom you can get information on these services?

### Feelings about screening

- 11. [For women] Have you ever had a pelvic exam or a speculum exam? (Explain, as necessary, this is when the health worker feels [pelvic exam] or looks [speculum exam] inside your vagina to check that everything is fine.) If yes, how did you feel about that experience? If no, how do you think you would feel about such an exam?
- 12. How would you feel about having a pelvic exam if it could help to prevent you from getting cervical cancer?
- 13. How do you think your women friends or relatives would feel about having pelvic examinations?
- 14. How do you think your husband or partner would feel about you having a pelvic examination?
- 15. [For men] How would you feel about having your wife or partner get a pelvic exam and a screening test if it could prevent her from getting cancer?

## Possible barriers to utilizing screening services

- 16. What has made it difficult or might make it difficult for you [men: "for your partner"] to go for cervical cancer screening services? (Explore by asking, "How about. . . ": your feelings about cancer and/or about the pelvic exam, your husband's or partner's approval, family approval, where the services are offered, who is providing the services, transportation problems, cost concerns, having to travel far, missing work, or having to get others to look after children.)
- 17. What would make it easier for you [for your partner] to go for cervical cancer screening services? (Explore, depending on the previous answers.)

## Attitudes toward the health care system

- 18. Where do you normally go for health care? For reproductive health care?
- 19. What do you think about the quality of services provided there?
- 20. Do they meet your needs?
- 21. How do you feel about the way you are treated when you go there?
- 22. Would you be comfortable going there for cervical cancer prevention services? If no, why not?
- 23. What could help you change your opinion?

## Location and timing of services

- 24. Where would be the best place for you to go for cervical cancer screening?
- 25. What would be the best time (time of day, day of the week, season of the year)?

## **Appendix 4.6. Sample Questions to Assess a Laboratory**

These are sample questions for interviews with laboratory directors, pathologists, technicians, and other key laboratory personnel to assess the histopathology laboratories. These questions could be adapted and modified to suit the specific situation concerning the health care infrastructure and laboratories in your country.

#### **National issues**

- 1. How many pathology laboratories exist in the country by health district/region?
- 2. Is the laboratory system centralized or decentralized?
- 3. Is there a national reference laboratory? Does it conduct external quality reviews of the cytology and histopathology conducted by the regional laboratories?
- 4. How many cervical cytology tests and cervical biopsy tests does each laboratory process on average each year?
- 5. What terminology is used by the laboratories to report results of screening tests and of biopsy tests? Is this standardized nationally?
- 6. How many cytopathologists and cytotechnicians exist in each laboratory? What type of training are they provided?
- 7. How many cervical cytology tests does each cytotechnician read on average on a daily basis and on an annual basis?
- 8. Is the quality of the cytotechnician's work evaluated and monitored to ensure quality of the cervical cytology test results? How is this achieved?
- 9. How is the quality of the pathologist's work evaluated and monitored to ensure quality of the biopsy test results?

#### **Local issues**

- 10. How does the laboratory register the reception of the tests? Is a unique identifier code assigned for each woman?
- 11. What terminology is used for notification of results? Who is responsible for the final report? To whom does the report go? Who is responsible for follow-up of abnormal test results?
- 12. How does the laboratory report the test result back to the corresponding health center/screening site? What linkages exist? How easy is it to access and retrieve these test results?
- 13. On average, what is the time delay from when a sample is received to when results are recorded and sent back to the health care site? On average what is the amount of samples that are backlogged for interpretation? What is the primary cause of this backlog?
- 14. What percentage of samples is lost to breakage during transportation?

- 15. What are the procedures for reception and daily recording of slides received (e.g., numerical order of receipt, date of receipt, full name, place that smear is taken)? Are these procedures done by hand or computerized?
- 16. What internal measures does the laboratory use for quality control?
- 17. Does the laboratory routinely correlate the abnormal screening test results with the histopathology results? If no, why not?
- 18. Is retraining offered for technicians who consistently have errors in interpretation?

## **Appendix 4.7. Sample Questions to Assess Information Systems**

These sample questions are for interviews with program managers, health administrators, HIS staff, data entry personnel, health providers, and others involved in recording and managing client information related to cervical cancer. These questions could be adapted and modified to suit the specific situation concerning the health care infrastructure and HISs in your country.

- 1. Is there a unique personal identifier in general use for health data? If so, is this a health system number or a more broadly used personal identifier?
- 2. How is information about cervical cancer screening and follow-up currently collected and organized? If this is not being done, what are the main challenges and obstacles to information collection and monitoring?
- 3. For what purpose does or could the program use the information system?

 Day-to-day screening operations (i.e., generating specimen
reports).
 Routine recall.
 Follow-up of positive results.
 Quality control.
 Statistical reports to labs, health centers, and/or test takers.
Statistical reports for program managers.

- 4. What process (log book, filing system, or computer system) is used or could be used to register information and test results for the cervical cancer program?
- 5. Are there standard reporting forms for screening, for diagnosis, and for treatment services?
- 6. Does the program have access to population counts for its target population (i.e., women in your target age range)?
- 7. Are there any other types of data that the cervical cancer program has access to which might be useful for improving a data system to manage and monitor the program (e.g., individual death records, hysterectomy records, etc.)?
- 8. Is there a cancer registry available in the country to monitor incidence and mortality rates from cervical cancer?

# Planning, Preparing, and Launching the Program

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## **Key Messages**

- Systematic planning is critical to the success of the program. Sufficient time should be allocated to plan a new program or to strengthen an existing program.
- A plan should be developed to define the targets, strategies, and actions
  for achieving high screening coverage, offering a high-quality and effective screening test, and ensuring treatment of women with positive
  screening test results.
- Decisions about the strategies to be included in the program plan must be informed by cost-effectiveness considerations. This means weighing the costs of various strategies against the impact they will have on the program.
- Sufficient financial resources need to be invested in the program in order for it to succeed. The allocation of resources must be strategic to maximize the impact of the program.
- Prior to launching the program, the systems and capacity for quality service delivery must be established so that providers can meet clients' right to quality care.
- Launch the program with an inaugural event to generate enthusiasm for its implementation among providers and community members.

## Introduction

Following the needs assessment, a program plan should be developed to describe the targets, strategies, and actions that will be implemented to achieve the program's overall goals. These goals should be to achieve a high screening coverage of the women in the target age group, make certain that the screening test is effective and acceptable, and ensure that all test-positive women are treated appropriately. It is important to allocate sufficient time up front (e.g., 6 to 12 months) to plan and prepare all programmatic components before launching a new program or a strengthened program. It is particularly important to ensure that all service elements are in place *before* launching the program in the community.

## Role of the Management Team

The management team's role is to map out local strategies that cover all programmatic areas, based on the needs assessment findings and considering cost-effectiveness. Specific tasks include:

- Defining the local programmatic targets, such as screening coverage and treatment for women detected with precancerous lesions.
- Developing the service delivery strategies for each component of the program: community information and education (I&E), screening services, and diagnostic and treatment services.

- Identifying the specific locations where services will be offered and determining the equipment, training, and resources (human and financial) needed at each site.
- Developing a program budget.
- Establishing systems for service delivery and quality management.
- Launching the program.

## **Cost Considerations**

When deciding which strategies to include in the program action plan, the management team must know the amount of financial resources that are available and how they will be allocated to each strategy. This is because the effectiveness of the program will be affected by the funds devoted to the strategies for achieving high screening coverage, offering high-quality tests, and ensuring treatment of test-positive women. However, there is a threshold beyond which adding more funds to the program will not necessarily yield proportional additional benefits to screening coverage, test quality, or treatment of test-positive women. This threshold will vary with countries, settings, and strategies used.

## Achieving high screening coverage

The strategies to achieve high screening coverage include making screening services widely available and accessible to women in the appropriate age group, as well as ensuring that people are informed about and aware of the importance of the services. Examples of activities include conducting large-scale promotional events or campaigns, contacting women and their partners in their homes, and sending health providers out to rural areas (mobile services). The relative cost-effectiveness of these strategies must be compared:

- Mobile services increase coverage by increasing accessibility to the services, particularly in rural areas, but they are costly and difficult to organize.
- In some settings, home visits and enumeration can be cost-effective, especially for estimating the size of the eligible population, advocating screening at the household level, and facilitating follow-up of women to be treated.

## Offering a high-quality, effective, and acceptable test

- Quality assurance procedures are necessary to achieve a high-quality screening test and accurate test results. The costs of initiating and maintaining a quality assurance component to a screening program must be formally considered.
- The relative costs and benefits associated with cytology screening programs are influenced by the maintenance of a constant and adequate workload for laboratory staff in order for them to maintain proficiency. With low workloads, the costs of the laboratory staff and equipment become high in relation to the effectiveness of the program.

- On the other hand, an excessive workload will reduce the quality of the screening test and compromise the effectiveness of the program.
- Visual inspection screening methods are associated with lower direct medical costs than cytology and HPV DNA testing because non-physicians can perform them, there is no need for laboratory support, and they involve less equipment and supplies. There are, however, costs associated with the thorough and ongoing quality assurance activities needed to achieve high-quality and accurate test results over time and these must be formally considered.

## **Ensuring treatment of test-positive women**

The ultimate effectiveness of the program depends on treating test-positive women, so that cervical cancer does not develop from precancerous lesions. Dedicating resources to reducing "loss to follow-up" (i.e., ensuring that women who are identified with precancerous lesions actually receive treatment) will have a great impact on program effectiveness. Thus, resources should be strategically allocated to strategies that may reduce loss to follow-up, such as generating up-to-date lists of women who need to be treated, having sufficient staff available to offer treatment services, and offering services at times that are convenient for women.

#### **Additional considerations**

In addition to these considerations, unexpected events like frequent staff absences or breakdown of equipment may increase costs and reduce program effectiveness. Program strategies that involve reducing the number of visits for women and reducing requirements such as sophisticated equipment or frequent training sessions may reduce the probability or impact of unexpected events and increase cost-effectiveness.

## **The Program Action Plan**

In the planning phase, the policy decisions made at the national level (e.g., target age group, coverage goals, and screening frequency) will be applied to the local program action plan in order to set *local* program targets. The local targets include the number of women to be screened in each service delivery area, the estimated number of women to be treated, and the most effective strategies for providing such services.

## Local screening coverage goals

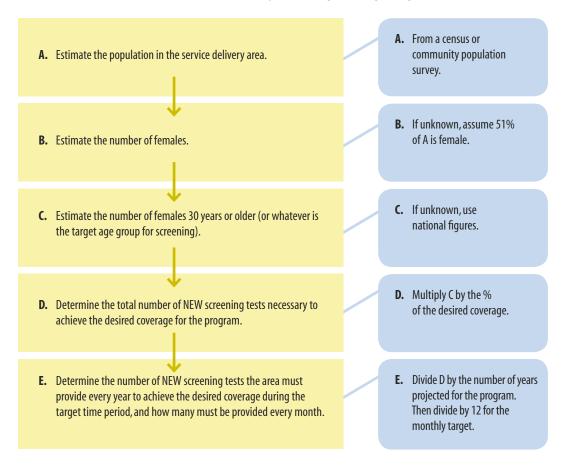
Coverage refers to the percentage of women in the target population who actually receive screening services during a given time period. Greater reductions in the incidence of cervical cancer will be achieved by ensuring that a large proportion of women are screened and treated for precancer. Screening of women outside the target age group or routine rescreening of the same women can reduce the effectiveness of the program. Therefore, objectives of the screening strategy should include screening women who have never been screened before and focusing on women in the target age group.

To achieve the desired coverage in a specified time period, the management team should estimate the size of the target age group in their area, and then calculate how many of these women need to be screened within a specified time.

Figure 5.1 shows a method to calculate the expected number of women to be screened on a monthly basis for a district or region over a given time period. The information needed for this calculation includes:

- Population of women in the target age group residing in the area.
- Coverage goal set by national policy.
- Number of years for the program to achieve its coverage goal.

**FIGURE 5.1.** Method to calculate the monthly screening coverage targets\*



<sup>\*</sup> This method assumes that no women in the target population have been screened; this is a reasonable assumption in most low-resource settings.

Source: Adapted from CHIP 2004a.

Population statistics of women in the target age group can be collected from census data (if available), by enumerating women in the target age group using a community survey, or from an estimate of the population in the area. An example of how to use this method to calculate the number of women to be screened is shown in the box opposite. This example does not account for annual population increases in the number of women in the target age group—an important consideration in program planning.

## **Example: How to Estimate the Monthly Screening Target**

In this example, the program's goal is to screen 80% of women aged 30 years or older, over a five year period, within a defined geographic area.

## A. Identify the size of the population in the area (e.g., from census data).

*Example*: The census reports that there are 250,000 people in the area.

#### B. Calculate the number of women in the area.

*Example*: Approximately 51% of the population is female. Therefore, there are an estimated 127,500 women in this area (51% of 250,000).

#### C. Estimate the number of women in the target age group to be screened.

*Example:* The census reports that 40% of the population is aged 30 years or older. Therefore, the estimated number of women aged 30 years and older in this area is 51,000 (40% of 127,500).

#### D. Calculate the TOTAL number of women to be screened.

*Example*: The program goal is to screen 80% of women aged 30 years or older, which is 40,800 women (80% of 51,000).

#### E. Calculate the MONTHLY number of women to be screened.

*Example:* 40,800 to be screened over 5 years = 8,160 women each year. Therefore, for each month the screening target is 680 women (8,160 divided by 12).

#### **Estimates for treatment services**

Follow-up diagnosis (where applicable) and treatment services will be required for all women with positive screening results. Therefore, the goal will be to provide these services to 100% of women who screen positive. In order to plan the strategies to achieve this goal and to budget for adequate staff and resources, the management team needs to calculate the number of women expected to have a positive screening test result that will require follow-up diagnosis and treatment for precancerous lesions. Table 5.1 provides an example of how to do this.

**TABLE 5.1.** Examples of estimating caseload of women requiring post-screening care

Category of client	How to estimate targets
Women screened positive who will require follow-up care.	Number of women screened times the screening test-positivity rate (5%–25% depending on the screening test used).
Women who will require treatment of precancerous lesions with cryotherapy.	80%–85% of women diagnosed with precancerous lesions will be eligible for cryotherapy treatment.
Women who will require referral for cancer management.	0.5%–1% of all women screened.

These estimates will be useful when planning and procuring supplies for the clinical services. For example, when planning and procuring cryotherapy supplies, it is useful to have an estimate of the expected number of cryotherapy treatments to decide on the number and size of cryotherapy gas tanks (nitrous oxide or carbon dioxide). See Appendix 6.2 for information on different tank sizes.

## Service delivery strategies

Once the screening coverage goals and estimated caseload for follow-up care have been established, the program plan should define how the services would be delivered in order to meet these goals and targets. This plan will include:

- Deciding whether to have a phased (vertical to integrated services) or combined (integrated plus vertical services) approach to implement the services.
- Deciding on the geographic locations and sites for screening and treatment services that will facilitate achieving coverage goals.
- Deciding on the supplies, equipment, and infrastructure needed for each service site.

#### Deciding on a phased or combination approach

New programs may benefit from the phased approach, which is to implement vertical services at the start of the program and later move toward integrated services (discussions of vertical and integrated services are found in Chapters 2 and 6). At the start of a new program, only a limited number of trained staff will be available. Having staff dedicated to only one health service is likely to promote higher commitment and focus on the objectives of the program. In addition, staff are likely to gain more experience performing the screening and treatment procedures. As the program matures, an increased number of staff will be trained and experienced and there will be greater community awareness to enable the program to move toward integrated services.

Countries with existing cervical screening programs may use a combination of integrated services and vertical services, for instance, integrating cervical cancer prevention services with general reproductive health services. They can be supplemented with vertical services, such as occasional mass campaigns.

## Deciding the geographic location for services

When deciding their target area, new programs will increase their chances of success by initially limiting the geographic scope of their activities, that is, by starting in a well-defined area and then gradually expanding to other regions as technical capacity and financial resources allow. Having a well-defined area facilitates achieving coverage goals for screening and increases chances of tracking women for follow-up. This "pilot phase" allows real-life testing of the service delivery approach chosen and provides important information on corrective actions that may be needed before expanding services to a larger area.

Information from the local needs assessment (see Chapter 4) can help management teams to identify areas with the greatest need and readiness, and to map appropriate locations for providing cervical cancer prevention services. Areas with the greatest need, however, are often the ones with the fewest resources. Both urban and rural settings have features that can limit or facilitate establishing and maintaining services. If the management team has the authority to select service delivery sites, they should consider the following factors:

- Geographic accessibility for clients.
- Ease of client tracking.
- Proximity to laboratories and treatment facilities.
- Range of human and equipment resources.
- Locations with large populations needing screening.

#### Decide on the supplies, equipment, and infrastructure

The supplies, equipment, and infrastructure for each service site need to be defined so that these will be sufficient to meet the screening coverage and follow-up targets. The information gathered during the needs assessment will guide the management team to decide on the specific equipment and supplies needed, as well as quantify the required equipment and supplies to achieve the coverage goals. The list of equipment and supplies required for a cervical cancer prevention and control program is contained in Appendix 6.1. Strategies for distributing and storing equipment and supplies must be established to ensure a constant flow to the health facilities. Mechanisms must also be established for repairing and maintaining equipment.

Planning activities related to other components of the cervical cancer prevention program—I&E, training, and monitoring and evaluation—are described in detail in Part 3. Planning activities related to cervical cancer treatment can be found in Chapter 10.

## The Program Budget

After establishing the program's goals, targets, and strategies, the management team needs to estimate the cost of carrying out the program plan at the local level. The required funds should be allocated based on the need for each service site to have adequate resources, including skilled personnel, equipment, and supplies to serve the anticipated number of women. The case study on the next page illustrates the costs of an organized screening project in a rural part of India.

Once the required funds have been determined, the management team should identify whether resources are currently available, whether additional resources are required, and where the new resources will come from. Existing human and material resources may be sufficient, but additional resources and funds will often be required. If resources are limited, it is advisable to begin a program in a smaller area and later expand services as additional resources become available.

## Case Study: Costs of an Organized Screening Project in a Region of Rural India

A large screening research project with a target population of 100,000 previously unscreened women has been established in rural Barshi, India, without preexisting infrastructure. Mobile clinics were used to screen women with VIA, cytology, or HPV DNA testing in the villages. Women who screened positive were provided transportation to the rural hospital for diagnosis and treatment. On average, the project screened 25,000 women per year.

About US\$1,000,000 was allocated to cover the full cost of all aspects of this project. The total cost per eligible women ranged from \$4.30 to \$12.40, depending on the screening test. Between 8% and 21% of these costs were attributable to program-level costs, including infrastructure changes, implementation and management, and establishing an HIS. Overall, recruitment and invitation accounted for between 6% and 17% of the total cost of screening women.

The preliminary results of the project showed that high levels of participation (79%) and treatment (83% of the women with lesions were treated) can be achieved and that a screening program can be established with satisfactory performance in a very limited-resource setting.

Source: Legood et al. 2003.

The next box provides a list of items to be considered when developing a program budget, whether it is for a new program or strengthening an existing program. This list assumes that the basic women's health service infrastructure is already established, and therefore resources are not required for basic start-up of services.

## Items to Consider in Developing the Annual Program Budget

### **Community involvement**

- Salaries and incentives for health promoters or CHWs.
- Printing of educational and promotional materials.
- Media (TV, radio, or other media announcements).
- Community education sessions:
  - Travel costs for personnel to visit communities.
  - Physical requirements (e.g., room, chairs, flip charts, materials).
  - Paper, photocopies, and other office supplies.

#### **Training**

- Payment for the trainer(s).
- Travel costs for the trainer(s) and trainees.
- Honorarium or per diem for health personnel to attend training sessions (if applicable).
- Physical requirements for training:
  - Room rental.
  - Gynecologic model (where used).
  - Presentation materials (projector, screen, paper, etc.).
  - Supplies for screening and treatment.
  - Invitations to women to participate in a gynecologic examination by health providers during their practical training session.
- Administrative support.

#### **Screening services**

- Salaries for health personnel involved in screening (including cytology laboratory personnel if applicable). Consideration should be given to the number and type of health personnel required in each health center to provide screening and the time required to perform the services.
- Equipment and supplies for primary health care centers for screening.
- Equipment and supplies for cytology laboratories to process screening tests.
- Clinical forms to collect information and record test results.



#### Diagnostic and/or treatment services

- Salaries for health personnel involved in diagnosis and treatment (including pathology laboratory personnel, if applicable).
- Equipment and supplies for diagnosis and/or treatment and palliative care (please refer to the detailed list of equipment and supplies contained in Chapter 6).
- Equipment and supplies for pathology laboratories to process biopsies (if used).
- Clinical forms to collect information and record results.
- Hospital-based care for women with cancer (this will probably be included in hospital budgets).

#### **Monitoring and evaluation**

- Salary for program staff for record keeping, data entry, generating progress reports, and computer support (where used).
- Paper, photocopies, and other office supplies for monitoring and reporting purposes.
- Computer and information system software for monitoring and reporting purposes (if applicable).
- Meeting costs (room, hospitality, travel) to meet regularly with area supervisors to discuss results.

### **Program support costs**

- Salary for program manager, administrative assistant, and other personnel required to oversee and manage the program.
- Transportation for the manager and the area supervisors to make supervisory visits to health centers.
- Transportation for sending screening test samples to the cytology laboratory.
- Transportation for sending histopathology samples to pathology laboratories.
- Recruitment of new health personnel and program staff.
- Storage and distribution of equipment and supplies to health centers.
- Repair and maintenance of equipment for diagnosis and treatment.
- Health center infrastructure, where it is needed (e.g., gynecology table).

## **Establishing Systems for Service Delivery**

Once the program action plan and budget have been defined, preparations need to be made to ensure that all the necessary systems to deliver quality services are in place before program launch. Establishing systems for service delivery means ensuring that the relevant program materials are developed and made available, linkages are established between community and facilities, providers are trained and available, equipment and supplies are procured and distributed, and stakeholders and staff are fully oriented on the program's goal and strategies.

Most of these preparatory activities will need to take place concurrently. In this regard, the management team will need to set realistic timelines, organize appropriate task groups, and coordinate these activities to ensure that all preparations are completed in a timely manner prior to launching the program. It is important to set up the systems and build capacity *before* launching services, so that clients will find facilities and staff ready when they seek services.

## **Develop program materials**

All necessary program materials required to support the program plan, such as I&E materials, training materials, and clinical forms, should be developed. If program materials currently exist, it may be useful to review them to determine whether they need to be modified. If no program materials exist, new ones will need to be created, based on the contents of the national policies.

Training manuals, curricula, and course agendas are developed by the trainers who will conduct the training. Developing I&E materials can require much time, effort, and resources. Wherever possible, therefore, it is best to adapt existing materials. The ACCP has ample such material, both for I&E and for training, which can be adapted and translated to ensure it is locally applicable and appropriate. These materials are listed in Appendices to Chapters 7 and 8.

## Establish linkages with community and facilities

An effective cervical cancer prevention program requires a well-functioning referral network to ensure continuity of care for the client. Program planners should set up a referral task team, develop referral protocols and tools, and identify and upgrade referral facilities, as well as establish and maintain feasible communication systems. In addition, linkages should also be established with laboratories, other health sectors, data processing centers, and above all with the community. Refer to Chapter 6 for details on establishing and maintaining linkages.

## Provide orientation for community, stakeholders, and staff

To promote the cervical cancer prevention program, both in the community and within the health care facilities, orientation to the program should be provided to all cadres of staff, stakeholders, and community groups. Their roles and responsibilities within the plan need to be clearly communicated so that they are prepared to participate in the program's implementation. They also need to be made aware of and familiarized with the program materials such as I&E material and clinical forms.

## **Ensure provider training and availability**

Before launching the program, the management team should ensure there will be sufficient numbers of qualified staff to attract women to services, provide screening, and treat those who test positive. Training should be conducted according to the plan developed. It is important not to conduct the clinical training too early in the program planning phase to avoid providers losing their newly acquired skills and enthusiasm. Refer to Chapter 8 for further information on training providers.

## Procure and distribute equipment and supplies

The health facility sites will need to meet basic requirements for service delivery such as running water, adequate ventilation and lighting, functioning equipment, and available supplies. Facilities should be available to store equipment, stock supplies, and file client records. Procurement and distribution of the necessary equipment and supplies should begin at least three months before launching the program. The following factors should be considered:

- Types of equipment and supplies needed.
- Sources (vendors) for procurement and resupply.
- Systems for requesting and delivering equipment and supplies.
- Storage capacity.
- Repair and maintenance of equipment.

It is important to ensure that an efficient supply distribution and logistics chain is in place. Often, the management team is familiar with systems for procurement, requisition, and distribution. For cervical cancer prevention programs, new sources and new types of equipment or supplies will probably have to be factored into the usual systems. The management team should identify sources for supplies and equipment, storage options, and requisition processes for each clinic.

Please refer to Appendices 6.1 and 6.4 for a list and illustrations of recommended equipment and supplies.

## Establishing Systems for Supervision, Monitoring, and Evaluation

Before initiating the program it is essential to establish systems for supervision, monitoring, and evaluation. This step involves building capacity—designating staff, providing appropriate training, defining program indicators, and developing tools for monitoring and evaluation.

## Set up the systems for supervision

A key aspect of ensuring quality in service delivery includes supervision at the facility and district levels. The management team should set up the supervisory systems before launching the program by designating and training the facility and area supervisors in their roles and responsibilities and by setting up a network for ongoing communication and monitoring.

The roles of the supervisor at the district and facility levels are to monitor and evaluate service quality, mentor staff, and facilitate communication with the management team. In addition, the nationally designated district-level supervisor will provide external supervision of all the facilities within his or her district and share experiences and lessons learned among the network of facility supervisors.

Supervisors need to be made aware of their roles and responsibilities, which include:

- Monitoring and evaluating service quality. Supervisors have a key role to play in ensuring that service staff keeps good quality records. They need to scrutinize site-level data with facility staff, looking at recruitment, coverage, screen-positive rates, turnaround times (where laboratories are used), specimen adequacy rates (cytology and HPV DNA testing), and treatment rates. Supervisors should help staff utilize such data appropriately for client management. Furthermore, supervisors play a key role in ensuring that data are collated and forwarded to the management team in a timely manner.
- *Training and mentoring*. Supervisors should provide oversight for organizing training, as well as for trainee follow-up. If clinically competent themselves, they may have a role to play in monitoring clinical competency and client-provider interactions, including counseling. To do so, they need to have been well trained themselves or be able to liaise with other specialists who can provide needed support.
- Establishing and maintaining communication among the network of providers. Where cervical cancer prevention services involve multiple client visits or referrals between facilities, the need for linkages among all service levels is paramount. The supervisor can provide this linkage by communicating and interacting often with providers and by fostering communication among the network of providers. They can establish and monitor the referral and feedback systems and facilitate regular meetings to evaluate how the system is functioning.
- Facilitating quality services. A key supervisory function is that of facilitator. The supervisor is often perceived as someone who comes to see whether staff are performing to standards. Supervisors must be trained not only to oversee quality assurance in a way that improves staff understanding of standards and guidelines, but also to develop the trust and respect from and among staff that will enable them to provide quality services. An additional role of the supervisor is to ensure that the training, equipment, and other needs of providers are met.

## **Build capacity to ensure quality**

Staff should be oriented and provided with practical, easy-to-use tools for continuous quality management. This measure includes giving staff the tools to help them identify problems and develop solutions using local resources. For example, the  $COPE^{**}$  (client-oriented, provider-efficient) self-assessment approach (EngenderHealth 2004) helps staff to continuously improve the quality and efficiency of services provided, and make services more responsive to client needs by identifying concrete and immediate opportunities for action. Chapter 9 provides further detail on tools for improving quality.

## **Define the program indicators**

The management team needs to identify the critical indicators that will be used to monitor program performance. For each of the program goals—achieving a high screening coverage, offering a quality test, and ensuring treatment of test-positive women—progress can be measured using appropriate quantitative indicators. Refer to Chapter 9 for further detail on the indicators, using them for monitoring the program and identifying areas needing corrective action. These indicators should be defined before launching the program.

## Set up the information system

Monitoring the program performance, based on the defined measurable indicators, requires an HIS that generates good-quality data in a timely manner. The management team will need to ensure that there is an HIS set up to collect, summarize, and report on the defined indicators. A fully functioning information system with efficient communication links should be set up before launching the program to avoid backlogs of information collection, as well as long delays in managing patient information. Refer to Chapter 9 for further detail on using the information system to monitor and evaluate the program.

<sup>\*</sup> COPE is a registered trademark of the U.S. patent office.

## **Launching the Program**

The program should be formally launched through an event with stakeholders, community, and health staff to announce and inaugurate the program. It should take place once all the preparations have been completed, including those for program materials, equipment and supplies, trained health providers, and the systems for quality management. The event could involve a large meeting with the policymakers, key stakeholders, community representatives,



Having a ceremony involving stakeholders, healthcare staff, and community members can effectively launch a new program.

and media to introduce the program, its strategies and materials, and to present formally the members of the management team and area supervisors. A community-based launch event will serve to profile the program and generate enthusiasm for its implementation among the providers and the community members. It is important to ensure that once the program has been launched, the services are offered immediately afterward with continuous implementation.

Part Three of the manual provides detailed information on implementing key aspects of the program.

## **Conclusion**

A program action plan and a budget allocating resources to the plan should be developed. The action plan should comprise local screening coverage goals, estimates for treatment caseload, and local strategies for service delivery, training, and I&E activities. These strategies need to be developed to achieve the program goals of high screening coverage, offering a high-quality test, and ensuring treatment of test-positive women. It is important that all systems and capacity to deliver cervical cancer prevention services are in place prior to inaugurating the program. Most of these preparatory activities will need to be performed concurrently. A vital role of the management team is to set up realistic timelines and coordinate the various activities. Once the program has been launched, services should be offered according to established plans to maintain support among providers and the community.

Three

# Implementing Key Aspects of a Program

Part Three of this manual provides detailed information on how to implement key aspects of a program, thereby ensuring that eligible women have maximum access to quality cervical cancer screening and treatment services.

- **Chapter 6** focuses on ways to ensure availability of screening and treatment services, establish and maintain a service structure that maximizes accessibility to clients, and build and maintain effective links between the community, laboratories, referral centers, other health services and health sectors, and data processing centers. Appendices list and illustrate equipment and supplies.
- **Chapter 7** provides information on various strategies that can be used to reach eligible women, provide counseling support to those women who seek preventive care, protect their rights, and improve their understanding of quality of care.
- **Chapter 8** introduces basic concepts about training followed by ongoing mentoring to ensure performance to standard. It also provides information on how to set up and implement a sustainable training system. The principles outlined apply to all cervical cancer screening and treatment methods and approaches.
- **Chapter 9** focuses on how to monitor program performance and ensure overall quality of care. It provides information on program indicators, health information systems (HISs), and quantitative tools and suggests corrective measures to improve program performance.

# Delivering Clinical Services and Strengthening Linkages

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## **Key Messages**

- Cervical cancer prevention services include counseling, a screening test
  (with or without a diagnostic test), and precancer treatment for women
  who test positive. A wide range of trained and competent medical personnel—physicians and non-physicians—can effectively provide these
  services.
- Reducing the number of clinic visits for screening, treatment, and follow-up increases program effectiveness.
- Supplementing the health center-based (static) approach with outreach clinical services to remote areas increases access to these services.
- To ensure continuity of care, a cervical cancer prevention program requires a well-functioning referral network and linkages with the community and other needed services.
- Consistent and reliable services are vital to ensure that clients who seek services are not turned away either because of the unavailability of providers, functioning equipment, or essential supplies or because of delays in obtaining laboratory results.

## Introduction

The effectiveness of any cervical cancer prevention program depends on screening a large number of eligible women and treating those with precancer. Several major factors can limit the impact of cervical cancer prevention services. Screening services may not be available or, when available, are inaccessible, underused, or unreliable. Precancer treatment using simple, effective methods such as an outpatient service may be unavailable, inaccessible, or inadequately linked to screening services. When simple treatment services are unavailable, more invasive and often inappropriate inpatient procedures (cold knife cone or hysterectomy) frequently are performed for women with precancer. They involve a hospital stay, as well as greater cost and potential for complications.

In addition, many women who are screened and need treatment for precancer do not return for treatments. This "lost to follow-up" rate can be as high as 80%, severely jeopardizing program effectiveness (EngenderHealth et al. 2003a, Gage et al. 2003). Clients fail to attend subsequent visits for various reasons: lack of appropriate counseling, previous poor experience at the facility, long delays in receiving test results, and long distance to the treatment facility. Also, programs often lack efficient tracking systems to contact clients to return for treatment and follow-up. Finally, lack of supplies and functioning equipment can lead to unreliable service availability and clients being turned away.

This chapter presents guidelines for delivering cervical cancer screening and treatment services that take these barriers into account. It is divided into three sections. The first addresses how to ensure availability of screening and treatment services. The next covers key decisions about service structure that affect accessibility to clients. The final section considers how to establish and maintain effective links

among community, laboratories, referral centers, other health services and health sectors, and data processing centers.

## The Role of the Management Team

The role of the management team is to design and implement cervical cancer prevention services to ensure that:

- Safe, effective, appropriate, and acceptable screening and precancer treatment services are available and accessible to eligible women in a timely manner.
- Services are well coordinated and efficient links are maintained with the various service components, for example, community, clinical, laboratory, and other health services and health sectors.
- Services meet the needs of women using a holistic approach and ensuring client's rights to continuity of care, privacy, dignity, and confidentiality.
- Functioning equipment and supplies, as well as trained staff are available at the service sites to ensure uninterrupted services.

Information is presented here to help the management team plan for a variety of approaches for cervical cancer prevention. It includes modalities for screening by cytology, HPV DNA testing, and visual tests (visual inspection with acetic acid [VIA] and visual inspection with Lugol's Iodine [VILI]). In addition, it includes modalities for diagnosis (colposcopy with or without biopsy) and treatment of precancer using cryotherapy or loop electrosurgical excision procedure (LEEP).

## **Ensuring Availability of Services**

This section focuses on key considerations in establishing cervical cancer prevention services: components of clinical services, personnel required, and preparing and sustaining service facilities. Clinical services for cervical cancer prevention should include counseling, a screening test (with or without a diagnostic test), precancer treatment for women who test positive, and access to or referral for treatment or palliative care for women found to have invasive cancer. Privacy should be ensured when providing the services. There are a variety of service delivery options, and the management team should select the option most suitable for the particular setting and program goals. Refer to Chapter 1 for details on the various screening and treatment methods.

## **Aspects of cervical cancer prevention services**

### **Counseling**

Counseling is an integral part of all cervical cancer prevention services and should be integrated in the training programs and supervisory systems. Counseling should be provided before each screening, diagnosis, and treatment procedure. Key counseling messages on tests results and the implications of the test results should be reinforced after the procedure, using both verbal and written instructions.

## Screening

Women in the target age group will need to be screened in accordance with the national policy on screening method and frequency of screening. Following the counseling and history taking, the screening test is provided and relevant findings documented. When visual tests are used, the provider determines if the test is positive or negative. For cytology and HPV DNA tests, the provider collects the test specimen, labels it, and completes the appropriate request forms to be sent with the specimen to the laboratory for processing. Further management of women with a positive screening test will depend on the



Women in the target age group should be screened in accordance with national policies.

screening test result and clinical management approach: traditional, intermediate, or the screen-and-treat approach. (Refer to Figures 6.1 and 6.2 and Table 6.2.) The specific requirements for screening in a given setting will be influenced by policy decisions on the screening methods, clinical management approaches, and the availability of infrastructure.

## Women with negative tests

The majority of women undergoing screening will test negative. Women with negative screening test results and women with negative diagnostic/confirmatory test results should be informed about the results. In countries with a policy of periodic rescreening, women with negative results should be advised to return for rescreening at the appropriate interval.

#### **Laboratory services**

Cytology and HPV DNA testing require laboratory services to process and provide results and involves multiple steps. These steps include packing the labeled test specimen, transporting the specimen to the laboratory, processing and evaluation in the laboratory, preparing the report of the test results, and then communicating the results to the referring facility.

When laboratory services are required, it is important to ensure that:

- Test specimens are appropriately labeled and packaged.
- Transport of tests and reporting of results are organized and coordinated. Laboratory and facility staff can collaborate to establish and maintain locally feasible transport systems. For example, on scheduled days of a week, a designated person delivers laboratory reports from the previous one or two weeks, collects specimens that are packaged and ready for pick up, and takes them to the laboratory.
- Standardized request and report forms are developed and available for use at the facilities.

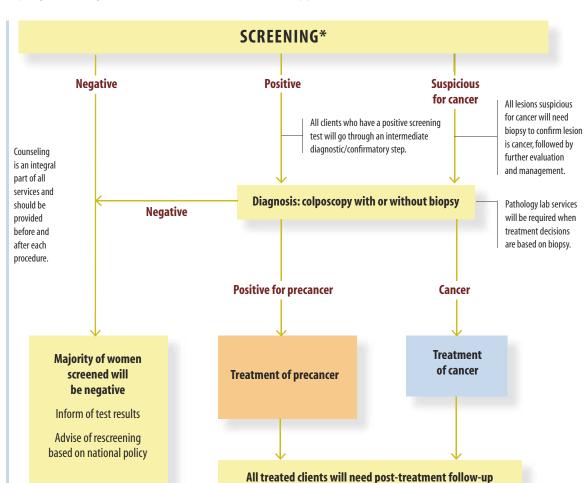
For information on organizing cytology laboratory services, refer to publications from WHO (1988) and PAHO/WHO (2001), listed in the Further Reading section at the end of this chapter.

#### **Treatment**

Regardless of the screening test used, screening must be linked to treatment to ensure program effectiveness. Treatment of precancer can be best provided using outpatient procedures such as cryotherapy or LEEP. The process of deciding who needs treatment is based on the process of detection and the treatment options available:

- Traditional and intermediate approaches. Clients with a positive screening test are followed up with a diagnostic step. In the traditional approach the decision to treat is based on the results of a colposcopically directed punch biopsy. In the intermediate approach the decision to treat is based on the findings from colposcopy. The intermediate approach can include post-treatment confirmation (e.g., through histopathological examination of a colposcopically directed punch biopsy taken prior to treatment). See Figure 6.1 for the sequence of steps involved in the management approaches.
- Screen and treat approach. Clients with positive screening test results are treated, usually using cryotherapy, bypassing the diagnostic step. (See Figure 6.2 for sequence of steps involved.) Clients whose lesions are unsuitable for cryotherapy are referred for further evaluation and treatment

A discussion of the implications these approaches have on the number of health facility visits a woman must make can be found on page 89.



**FIGURE 6.1.** The sequence of services required for cervical cancer prevention and treatment program using the traditional and intermediate approaches

#### Women suspected to have cancer

Whether using the traditional, intermediate, or screen-and-treat approach, women who are suspected of having cervical cancer need to be further evaluated and treated appropriately.

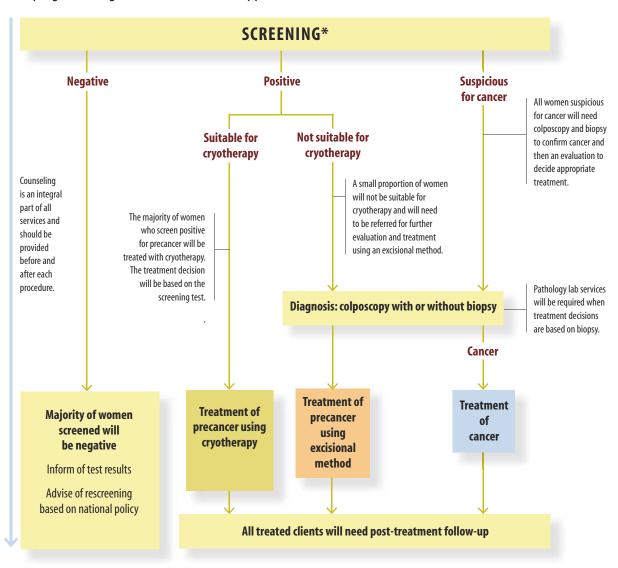
### Post-treatment follow-up

All clients who have been treated for precancer should be followed up to confirm a cure. It is recommended that this be done at a minimum one-year post-treatment. An earlier visit to provide support is optional. If possible, they should be followed up yearly for up to five years. A repeat screening or confirmatory test is recommended at routine follow-up visits.

All women who are treated for cancer need to be followed up by the organization providing cancer care after treatment per the established protocol. (See Chapter 10.)

<sup>\*</sup>Laboratory services will be required for cytology and HPV DNA tests.

**FIGURE 6.2.** The sequence of services required for cervical cancer prevention and treatment program using the screen-and-treat approach



<sup>\*</sup>Laboratory services will be required for cytology and HPV DNA tests.

### Infection prevention

Just as in all other clinical services, infection prevention is an integral part of all cervical cancer prevention services. Refer to the Further Reading section of this chapter for sources of information on infection prevention.

## Personnel for providing cervical cancer prevention services

A wide range of trained and competent medical personnel can provide cervical cancer screening and treatment. The decision on who can perform specific procedures should be based on national norms and regulations and should be made jointly with the relevant in-country professional organizations. Within these guidelines, the management team should ensure that staff roles and responsibilities are well defined, and that staff are trained to do the job (see Chapter 9). Table 6.1 provides a list of the medical personnel who, when trained and competent, can potentially provide the relevant services.

**TABLE 6.1.** Personnel for providing cervical cancer prevention services

Services	Potentially Appropriate Medical Personnel
Screening (cytology,* HPV DNA test,* visual test)	Physicians (general practitioners, gynecologists) and non-physicians (nurses, nurse-midwives, family nurse practitioners, clinical assistants, primary health workers)
Cryotherapy	Physicians (general practitioners, gynecologists) and non-physicians (nurses, nurse-midwives, family nurse practitioners, clinical assistants, primary health workers)
Colposcopy and biopsy*	Physicians (general practitioners, pathologists, gynecologists) and non-physicians (nurses, nurse midwives)
LEEP	General practitioners or gynecologists
Cold knife cone (under general or regional anesthesia)	Gynecologists

<sup>\*</sup>Cytology, HPV DNA testing, and histology (biopsy analysis) will require appropriate laboratory personnel for processing.

All providers performing client assessment, screening, and treatment should be skilled in client-provider interactions, including counseling. If it is feasible, a designated counselor can provide significant program benefit. All providers performing clinical services should comply with infection prevention practices. Any trained personnel can disinfect and process relevant equipment and supplies.

# **Preparing and sustaining service facilities**

Screening and treatment services should be provided in a consistent manner on scheduled days. Service hours for screening and treatment should be defined and prominently displayed on signposts at the facility and also should be stated during promotional activities. Making services available in the late evening on designated weekdays or on Saturdays may be necessary to ensure services are accessible to working women. Client registration should be organized to minimize waiting time.

Clinic rooms should have functioning equipment and be stocked with appropriate supplies necessary to perform and document the procedure. The management team should identify one person at each site who will be responsible for ensuring that adequate equipment and supplies are available. This person should keep track of stocks and monitor the equipment so that requisitions for resupply or repair are made in a regular and timely fashion.

At hospitals and health centers in most health care systems, there is usually at least one person who is responsible for maintaining equipment. Training these individuals to maintain instruments and ensure that they are repaired (locally or at a distant location) increases the efficiency of the entire operation. It is much less expensive to maintain expensive instruments than to replace them. The management team must also identify local personnel who have the skills and experience to repair equipment (e.g., equipment required for colposcopy, cryotherapy, and LEEP). It is unlikely that nurses or physicians will be appropriate for this type of role; instead, management teams should consider using local repairmen, who can be trained in the special repair and maintenance skills required. Sources for repair supplies and spare equipment will need to be identified.

Once implementation of services begins, the management team will discover that even the best-laid plans sometimes go astray. Unanticipated events, such as stockouts and distribution problems may interrupt the availability of supplies. Equipment can break or fail. Such challenges are opportunities for the management team to assess existing mechanisms for procurement and resupply. To the extent possible, it is best to use local solutions to address these problems. Sustaining a service delivery site requires good communication between the management team and site personnel. Management teams must be willing to involve site personnel in developing solutions to problems (see Chapter 10).

A cost recovery/sharing system to replenish consumables (vinegar, glass slides, cotton swabs, etc.) and to fund repair and replacement of facilities and equipment can facilitate sustainability. The box below provides examples of activities that can be implemented as local resource-generating activities and/or to support women who cannot afford to pay the cost of the services.

# Examples of Facility-Level or Community-Level Activities to Facilitate Cost Recovery

Facility level. Each client contributes a small amount of money for screening and treatment services or each client replaces expendable supplies such as cotton. This contribution can be used to replenish supplies and/or to provide services for women who cannot afford to pay fees for the services or the cost of the supplies.

Community level. A group of women come together to help each other financially. Each member of the group contributes money to a group fund. Money from this group fund is then allocated to women on request for specific needs, including to pay for services or supplies. The women who use this money reimburse the group fund within a specified time.

# **Ensuring Access to Cervical Cancer Prevention Services**

The main goal of service delivery is to enable eligible women to have maximum access to quality cervical cancer screening and treatment services. Simply making the services available is insufficient to ensure use of services. Women in many countries—and particularly women in rural areas—have limited access to health services due to living long distances from health centers, transportation costs, family or work responsibilities, and other barriers. Programs that reduce the number of clinic visits required for screening, treatment, and follow-up make it easier for women to receive the care they need, increase follow-up, and reduce program costs.

# Single- versus multiple-visit approaches

Some screening methods and management approaches allow detection and treatment to occur during a single visit, while others require as many as three visits to the facility, referred to as the "multiple-visit approach." (See Chapter 1 for the various screening and treatment options.) Table 6.2 provides information on the number of visits in relation to the various screening methods and management approaches. It might be necessary to use more than one approach within a region and will depend on the location and capacity of the facility. For example, in one region some programs may lack adequate staffing to perform cryotherapy and so they may utilize a multiple-visit approach in which cryotherapy is performed at a referral site. Other programs in the same region may have staff who are capable of performing cryotherapy and thus these programs may opt for the single-visit approach.

**TABLE 6.2.** Clinical management with single-visit or multiple-visit approaches

	Clinical	Number of visits based on clini	cal management ap	proaches
Visits to facility	management approaches	Visit 1	Visit 2	Visit 3
Single-visit approach	Screen-and- treat approach	Visual tests* → Cryotherapy		
	Intermediate approach	Visual tests* → Colposcopy → Treatment		
Multiple-visit approach	Screen-and- treat approach	Cytology or HPV DNA test or visual test*	Treatment	
	Intermediate approach	Cytology or HPV DNA test or visual test*	Colposcopy → Treatment	
	Traditional approach	Cytology or HPV DNA test or visual test*	Colposcopy → Confirmatory biopsy	Treatment

<sup>\*</sup> Visual tests are VIA or VILI.

#### Single-visit approach

When test-positive women are treated immediately following the screening test (i.e., during the same visit), the method is referred to as a "single-visit approach." This method is currently feasible with visual tests because they provide immediate results using the screen-and-treat approach or the intermediate approach (see Table 6.2). The majority of clients with precancer (more than 85%) can be managed using cryotherapy immediately following the visual test with or without colposcopy. About 10% to 15% of women will require referral for further evaluation and management, either because the lesion is unsuitable for cryotherapy or the provider decides that further evaluation is required for other reasons (e.g., infection). The woman may also prefer to consult with her partner or family before being treated.

For many women, returning for multiple visits is a significant burden due to financial, practical, and logistical obstacles. A single-visit approach that reduces these obstacles by minimizing the number of visits needed can thereby reduce the number of women who do not return for treatment after screening. Even in some primary care settings offering visual tests, however, the single-visit approach might not always be feasible because inadequate resources or low client load prevents these facilities from offering cryotherapy. Since post-treatment follow-up is necessary, a tracking system (see under multiple-visit approach) will need to be set up to ensure that follow-up occurs.

#### Multiple-visit approach

Multiple visits might be required for all three clinical management approaches (screen and treat, intermediate, and traditional), as described in Table 6.2. As mentioned above, the major drawback of the multiple-visit approach is that clients needing treatment may fail to return. In addition, tests requiring laboratory support can have long delays due to various logistical issues, often related to geographic distance, transport problems, heavy workload, or backlog in the laboratory. Since getting results can be unpredictable and can take from one to six months or more, it is difficult to schedule client follow-up appointments for results and possible treatment. There is also the possibility that long delays may affect the validity of previous screening or diagnosis results (e.g., through disease progression or regression in the interim period).

Due to these delays, many women do not return for their results or, when they do return, the results are not available or have been lost. In many settings, tracking systems to identify clients who do not attend treatment or post-treatment follow-up, as well as communication systems to contact clients, are lacking or not functioning.

When a multiple-visit approach is used, it is important to ensure that:

• Subsequent visits for test results and treatment are scheduled as soon as possible after the screening visit. Whenever possible, the next appointment should be made at the screening visit. This arrangement will require effective links with laboratory and referral centers and a rapid turnaround of test results.

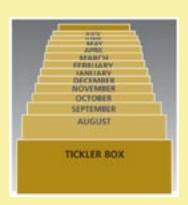
- Counseling messages must emphasize the need to return for subsequent diagnostic and/or treatment visits and post-treatment follow-up, when indicated. Verbal instructions should be reinforced with written instructions.
- An efficient tracking system should be in place to note when clients are scheduled to return and how to contact them if they do not. A reliable system to communicate the need for a subsequent visit should also be in place.

Methods used to track clients can vary and will depend on their appropriateness to local circumstances. Innovative ways often have to be developed. The elements of an effective tracking system are:

- Gathering and documenting client contact information at the initial visit and updating the information at each subsequent visit. For a population prone to frequent relocation, gathering and documenting information on a variety of contact sources might be necessary.
- Providing each client with her own patient card so she can keep track of her visits (see Appendix 9.1).
- Organizing a system to flag records (e.g., a "tickler box") to identify records of clients needing treatment or post-treatment follow-up (see box below). Such a system can be used to develop a list of clients to be contacted.

# "Tickler" System

A "tickler box" is a simple cardboard box used in a facility to track client



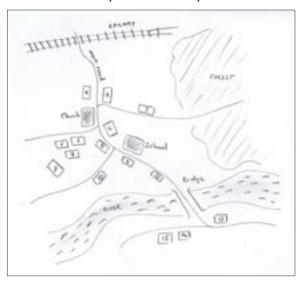
follow-up. The system consists of a box with dividers organized according to weeks or months. For each week or month, client follow-up cards are kept in alphabetical order by client's name. When a client has to be contacted to convey results, to provide treatment, to follow up post-treatment, or for rescreening, the health service provider fills out a card for the client. The card records the client's card number/ID number, contact details, date and results of the test, and

date when the client should attend. The card is then slotted into the box in the appropriate time period. Each week or month staff must check whether clients that were meant to return then have been seen. If not, the individual clients will need to be contacted.

Source: Adapted from CHIP 2004a.

• Communicating with clients, where feasible, informing or reminding them of their follow-up visit either by mail or phone calls. In many developing countries, however, rural areas and informal settlements lack reliable postal or phone services. CHWs or other outreach workers (e.g., community organizers) can play a vital role in making home visits to encourage clients to return for treatment or follow-up. Since precise addresses to locate clients' homes are often lacking in many rural areas, a simple map for the local area (e.g., a village) can be used to locate clients' houses. The map indicates the client's house number, which can be recorded on the client's information card (see Figure 6.3).

**FIGURE 6.3.** Examples of local maps used to locate clients





A map of a specific locality, neighborhood, or village should be used to identify clients' houses. The houses are numbered as reflected in the maps above so that specific houses can be located. Each client has her respective house number noted on her client information card.

# **Vertical (nonintegrated) services versus integrated services**

Both single-visit and multiple-visit approaches can be provided using vertical or integrated services. Health services tend to be integrated more often in primary care facilities, whereas services tend to be less integrated in secondary-level facilities.

#### **Vertical services**

In vertical services, providers and facilities are dedicated to only one health service. In addition, vertical services also exist within a comprehensive health facility when only a limited number of trained staff are available to provide cervical cancer prevention services. For example, a health facility may have a separate room, a separate appointment system, and specified staff assigned to work only on cervical cancer prevention. Clients may need to return for different services at different times. This situation has the characteristics of a vertical service from the clients' perspective.

Vertical services can be provided at static sites at all levels—primary, secondary, and tertiary—as well as by outreach clinical services (mobile units) as a regular (weekly, biweekly, or monthly) activity, through satellite clinics or an occasional mass campaign (see next section, on static and clinical outreach services).

#### **Integrated services**

Integrated services can be implemented when a large range or number of staff, including nurses and doctors (general practitioners and specialists) provide other health services and can incorporate cervical cancer prevention into their routine practice. During regular service hours, a client can access more than one health service from a single provider (e.g., general health services, family health, antenatal care, family planning, STI treatment, occupational health). Integrated services can be offered through static facilities or outreach clinical sites.

#### Static versus outreach clinical services

The choice of *where* and *when* to deliver cervical cancer prevention services should be made with the objective of optimizing access for clients. Cervical cancer prevention services can be delivered using static facilities, outreach services, or a combination of both.

"Static" services are those that are offered regularly at an established facility, such as a health center, clinic, or hospital. Outreach clinical services (sometimes called "mobile" services) are those that use a variety of facilities—schools, churches, or even health centers—to provide services by bringing in the necessary staff, equipment, and supplies for a set time. (A "mobile" service does not mean services are always provided in a vehicle, although this may be one approach to clinical outreach services.) Both static and clinical outreach services have strengths and limitations, as presented in Table 6.4.

**Table 6.4.** Strengths and limitations of static and outreach clinical services

	Static clinical services	Outreach clinical services (mobile)
Strengths	<ul> <li>Better availability and storage of equipment and supplies.</li> <li>Easier continuity of care.</li> </ul>	<ul> <li>Higher coverage through taking services to the clients; increased community participation.</li> <li>More convenient for client, as less time and money are spent to travel to a distant static site.</li> </ul>
Limitations	On-going efforts     required for inreach     (see Chapter 8) and     promotional activities.	<ul> <li>Requires intensive planning, organization, and coordination (equipment, staff, community linkage).</li> <li>Cost and time for "mobile" team, linked with type of transportation, geographic terrain, access, and quality of roads.</li> <li>"Field" conditions in the temporary facilities may lead to a lower quality of care.</li> <li>Logistical difficulties for handling laboratory samples.</li> <li>Limited time for counseling; less privacy; client information may be compromised due to time and peer pressure.</li> </ul>

#### Static clinical services

Cervical cancer prevention services can be provided as a regular service through all static facilities. All screening tests and cryotherapy treatment can be provided at all levels of health care (primary, secondary, and tertiary). Since primary care facilities are accessible to a larger proportion of the population than secondary or tertiary facilities, provision of screening and precancer treatment services through primary care facilities enables greater access to services and the potential for wider participation of eligible women. Treatments for precancer using LEEP and cold knife cone are best done at secondary or tertiary facilities because they require trained, experienced personnel and specialized equipment. Treatment of invasive cancer is usually centralized in tertiary facilities, since this requires highly skilled, experienced personnel, and expensive, high-maintenance equipment. Because the links between static facilities are usually better established than occasional clinical outreach services, the static approach offers greater continuity of care when clients' needs change or different levels of service are required.

#### **Outreach clinical services**

Outreach clinical services can play an important role by providing services to clients living in remote rural areas, thereby increasing the potential to reach women who are underserved by static health services. An outreach clinical team (sometimes called "mobile unit") usually comprises a skilled provider, an aide or assistant, staff to do registration and recording, and a community mobilizer. This unit brings special equipment and supplies with them to provide cervical cancer prevention services. Examples of mobile clinics can be found on pages 96–98.

All screening methods can be provided through outreach clinical services. It is logistically feasible to offer cryotherapy through outreach facilities by refilling carbon dioxide tanks and transporting cryotherapy units between sites. It is also possible to provide colposcopy and biopsy services using mobile units. However, colposcopy requires more expensive equipment and the availability of experienced colposcopists, which can be difficult to obtain. Mobile teams can provide LEEP and cold knife cone at secondary-level hospitals that have the necessary infrastructure but lack experienced providers.

When outreach clinical services are used, it is particularly important to pay attention to clients' rights and providers' needs and to ensure that quality is not compromised in any way. Client's rights to privacy, dignity, confidentiality, and continuity of care can be compromised when services are provided in temporary facilities. Counseling, too, may be limited by lack of time and privacy.

Because outreach clinical services are often provided through temporary facilities, they require more detailed planning, made in conjunction with the community and the staff at the distant site. Preparation will require decisions about and planning for locations needing outreach clinical units, working with community leaders in each location, assessing the suitability of each facility, and planning appropriate promotional activities (see box below).

# **Steps for Planning Outreach Clinical Services**

- Schedule dates, taking local events into consideration.
- Communicate and synchronize promotional activities well in advance.
- Define the roles and responsibilities of the team members and communicate this with the team.
- Recruit/organize a mobile team of trained providers and ensure their availability on the scheduled dates.
- Organize dependable transport appropriate for the team and their equipment.
- Ensure that all needed equipment and supplies are ready. Checklists can be used to ascertain this (see Appendix 6.3).
- Coordinate with referral facilities as necessary to provide treatment for all women testing positive on the screening test (when cryotherapy is not offered), for women unsuitable for cryotherapy, for managing rare but possible complications, and for managing other health problems.

Outreach clinical services can provide cervical cancer prevention either through mass campaigns or satellite clinics.

eling teams. Mass screening services can be organized as a time-limited, occasional event designed to systematically cover geographic areas where static services are unavailable or inaccessible. Single-visit approaches are better suited for this activity since they reduce loss to follow-up and overcome many of the logistical issues



Mobile services can successfully make screening services available to women in remote areas.

involved in ensuring continuity of care. If a multiple-visit approach is used, it is mandatory that referral systems for providing treatment are organized and functioning. Screening tests, such as cytology and HPV DNA tests, require laboratory support for results prior to providing treatment for precancer, so it is important to inform local laboratories about mass screening days to enable them to prepare for the extra workload that will be generated.

• Satellite clinics. Regular weekly, biweekly, or monthly cervical cancer prevention services can be provided relatively easily by outreach clinical teams visiting existing health facilities, using either the single-visit or multiple-visit approach. Multiple-visit approaches are more feasible with satellite clinics than with mass campaigns, because clients can more easily return to the site for follow-up, and coordination with laboratories is easier to organize.

#### Case Study: Mobile Services in Roi Et Province in Thailand

Mobile teams were engaged to provide services at satellite "subdistrict" health centers in addition to static services at the district hospital. The project was initially piloted in four districts of Roi Et Province. This project used the screen-and-treat approach using VIA and cryotherapy.

Within each district hospital, a team of trained nurses offered both static and mobile services. These service providers assisted their local hospital authorities to define the schedule for static and mobile services within their respective districts. Service delivery schedules varied from district to district, but in general static services were offered about three times per week. In those districts where mobile services were offered, mobile team visits to that district's satellite health centers were scheduled intermittently, so that each health center received at least one mobile team visit per month.



In advance of the scheduled mobile team visits, health center staff coordinated outreach and recruitment activities. This task was accomplished by identifying eligible women based on comprehensive subdistrict population registries, followed by public announcements within each village center engaging an extensive network of village health volunteers. These volunteers are informal, yet essential, members of local health promotion teams. As with other types of health promotion activities, the village volunteers used loudspeaker systems to draw the attention of local women.

On average, approximately 20 to 40 women were tested at each mobile team visit; for test-positive women, cryotherapy treatment could be performed immediately at most of the health centers. On the rare occasion when cryotherapy could not be performed for a test-positive client, providers referred her to the district hospital for treatment the following day.

Mobile services were more heavily utilized than static services, which suggests that mobile services are more accessible and acceptable to women. Districts offering exclusively static services performed 63 VIA tests per month; by contrast, those districts offering mobile services at least three times per week performed 226 tests per month.

#### **Case Study: Mobile Services in a Rural Guinea Project**

This visual screening project took place in the administrative subdistrict of Khorira in Guinea. The area covered includes more than 20,000 inhabitants. The closest gynecological facilities are in the city of Dubreka (more than 50 kilometers away), radical surgery was available only at Donka Hospital (in Conakry, about 200 kilometers away), and the nearest referral for radiotherapy was in Senegal. The decision to treat was based on colposcopy, and cryotherapy was the main method of treatment.

#### Step 1: Preparing for the mobile services

The initial step was to identify a cluster of villages with an expected target population of about 100 women. Local administrative authorities then identified local stakeholders (school teachers, village leaders, etc.), contacted them, gained their support, selected the most suitable days in the week for the mobile services, and selected the site for the mobile services (local primary health centers, municipal offices, schools, women's club buildings). A weekly schedule for offering mobile services was developed based on input from local stakeholders. A system for referral was organized with a facility in Dubreka and Donka Hospital. The mobile team consisted of staff from the regional hospital and the nearest health center: four nurses, a gynecologist, a counselor who also did the client



registration, a community mobilizer, and a nurse's aide. The necessary instruments and supplies were brought from the regional hospital to the clinic. A checklist was used to ensure that all necessary equipment and supplies were available and functioning.

#### **Step 2: Delivering the services**

Day 1 (Monday). Senior medical staff and a local administrative authority met with the local leaders to update them about the project and initiated site preparation.

Day 2 (Tuesday). A local health worker and a mapper performed house-to-house visits in order to enumerate eligible women and invite them to use the services. A local map was developed to locate the women. Information on the services was provided on a one-on-one basis, and each woman was provided with a pamphlet on screening that indicated where the mobile clinic would take place at 9:00 a.m. the next day.

Day 3 (Wednesday). Counseling, client assessment, and screening were provided at the site. Each woman was provided with a personal screening card. A nurse performed the client assessment and the screening test. In the same outreach clinic on the same day, all women with a positive visual test had colposcopy and were assessed to determine if they were suitable for cryotherapy. Women eligible for cryotherapy were treated on the same day. Biopsies were taken for all patients with abnormal colposcopy results, and specimens were sent at the end of the day to the pathology laboratory at Conakry for analysis, enabling the histological confirmation.

#### **Organization of referrals**

Women not eligible for cryotherapy or those who preferred not to have cryotherapy at the same visit were given an appointment at the regional hospital within two weeks. Women who were suspected of having cancer were referred to the University Hospital. Women were advised to visit the closest health center or the regional hospital if they had any problems following treatment. All appointments and mobile clinic findings were written on the personal screening card.

# **Establishing and Maintaining Linkages and Referral Systems**

An effective cervical cancer prevention program requires a well-functioning referral network, which facilitates continuity of care by linking the service facility with referral facilities, other health services, laboratories, other health sectors, data processing centers, and the community.

Health systems and their referral networks can vary from one country to another. In most developing countries, clients can attend any level of facility, and often their choice is based on convenience or previous experience. Some countries have a health system with two levels of care—primary and specialist—wherein clients can only see a specialist through referral from a primary care physician. Each of

these health systems presents challenges to establishing referral networks that are specific to that system. As it is beyond the scope of this chapter to address the specific challenges that may be faced within any one country or within a health system, this section will address the important aspects that are generally considered necessary for a referral system.

#### When and where to refer a client

Reasons for referral will depend on services available at the screening facility, the specific screening and treatment modalities used, and the clinical management approach used (traditional, intermediate, screen and treat). Table 6.5 shows the clinical services that may require referral and the level of facility providing these services.

**TABLE 6.5.** Indications for referral, service required, and level of referral facility

Indication for referral	Clinical service	required	Level of referral facility*
Clients testing positive for precancer	Treatment	Cryotherapy	Primary/secondary/tertiary level
		<ul> <li>LEEP</li> <li>Cold knife cone for women who are not suitable for cryo- therapy or LEEP</li> </ul>	Secondary or tertiary level
Major complications following treatment (e.g., severe bleeding, acute infections)**	<ol> <li>Blood trans</li> <li>Manageme</li> </ol>	control bleeding sfusion nt of infection— s (IV) antibiotics	Secondary or tertiary level providing inpatient 24-hour services, 7 days per week.
Suspicious of cancer	laboratory test Treatment (rac	opsy +/- colposcopy, is, staging) lical surgery, radiotherapy, , palliative care)	Tertiary-level facility or oncology centers. Requires interdepartmental and community linkages (see Figure 6.4).

<sup>\*</sup> This will vary, based on the cadre of provider at the facility, and may differ by country or region.

#### **Referral networks**

An efficient referral network should be a two-way system, involving the smooth transfer of information between facilities and facilitating client management at all levels and for all needed care. Referral networks vary based on the services available at each facility, the proximity of referral facilities, and the structure of the health care system. Referral networks for cervical cancer prevention will almost always require linkages between primary, secondary, and tertiary care facilities, or between public- and private-sector facilities. For example, when only screening services are provided at the primary level, clients will need referral to the closest

<sup>\*\*</sup> Major complications are rare. Minor complications such as vaginal discharge, spotting, or pelvic discomfort can often be managed as an outpatient procedure at the screening facility during regular working hours.

secondary- or tertiary-level facility for diagnosis and/or treatment, for the management of complications, and for other health services.

#### Identifying facilities to include in the referral network

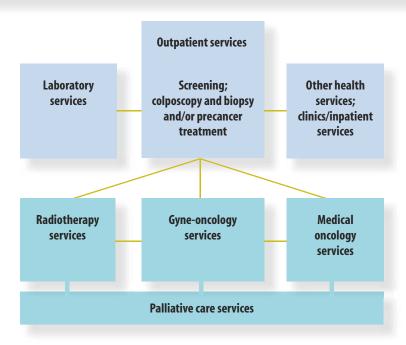
When developing a referral network, the management team needs to identify those facilities that provide the needed services (see Table 6.5), that meet standard requirements for quality of care, and that are accessible to clients, both in terms of service hours and location. The client's accessibility to a referral facility will depend on the reason for referral as well as the client's individual preferences. Whenever possible, referrals should be provided to those facilities that are most convenient for the client.

#### Referral networks between services

In addition to referral networks between facilities, an interdepartmental referral network, as illustrated in Figure 6.4, is essential for tertiary facilities that have multiple departments, to coordinate cervical cancer prevention and treatment as well as to provide other health services and inreach activities. ("Inreach" refers to organized information and education efforts that target patients and staff within health care facilities and is discussed further in Chapter 8.)

FIGURE 6.4. Linkages between services and community

# **Services Within a Community**



# Organizing and maintaining referral networks

The guiding principles for an effective referral network are:

- Involve stakeholders from the outset.
- Foster good relationships between the staff of the referral and referring facilities.
- Build mutual understanding on referral practices and the importance of timely communication between the staff at the various facilities.

#### Developing a referral task team

A referral task team—consisting of key stakeholders and representatives from the facilities providing screening, treatment, and laboratory services—can be organized to establish and maintain linkages. They should meet periodically (bimonthly, quarterly) to establish goals, agree on communication protocols and forms, review progress, and solve problems.

# Case Study: Ghana

The single-visit approach to cervical cancer prevention using VIA and cryotherapy was implemented in two sites in the Greater Accra Region of Ghana, namely Ridge Hospital, a regional hospital in Accra, and Amasaman Subdistrict Health Center, a rural hospital.

In principle, referral mechanisms for cervical disease in the Greater Accra Region are based on the concept of district or subdistrict health centers serving as initial screening centers, with referrals for advanced disease or diagnosis triaged to centers at Ridge Hospital or the University of Ghana Medical School's Korle Bu Teaching Hospital, both public facilities approximately 20 kilometers away from the Amasaman Subdistrict Health Center.

The project established a two-tiered referral protocol; all project staff were oriented to the protocol, as well as all associated forms. Ridge Hospital served as the initial referral point for all test-positive, treatment-ineligible women from Amasaman. Skilled and experienced gynecologists at Ridge Hospital assessed referred clients, treated precancerous lesions, and were prepared for the management of any post-treatment complication that might arise. For clients suspected to have cancer, punch biopsy was taken, and if histology confirmed cancer, the client was referred to a Multidisciplinary Cervical Cancer Care Group, or "MC3" (similar to "tumor boards" in developed countries) at Korle Bu. Clients referred to MC3 were given special referral forms that described their test status, biopsy results, and the referring gynecologist's recommendations. Following initial assessment by a gynecologist at Korle Bu, the case would be discussed by the entire MC3 and managed as per cancer management protocols.

Preliminary lessons drawn from implementation of this two-tiered referral system in Ghana suggest that feedback (counter-referral) continues to be the weakest link in the system and needs to be reinforced in an ongoing



manner. All referred clients who followed through on their appointments received care; however, written clinical reports from MC³ were infrequently shared with staff at the referring facility. Information sharing and feedback regarding referred clients did occur during monthly project meetings. All project staff from Ridge and Amasaman and at least one member of MC³ routinely participated in these meetings. Providers at referring facilities report that they value the communication links established with the departments of gynecology, pathology, and radiation oncology at Korle Bu, and they hope to maintain them.

#### Referral protocols

It is essential that health staff have clear written protocols for referral. These protocols should be developed by the referral task team with input from staff at the respective facilities and should conform to local or national health system policies. Protocols should include:

- Clear instructions on reason(s) for referral.
- Name, location, and service hours of the referral facility or facilities.
- Specific department for referral.
- Relevant information that should be recorded in the referral letter (date and time of referral, reason for referral, clinical findings, results of relevant tests).
- How to schedule appointments (if necessary).
- Instructions on organizing and using transport.
- Method of communication to be used between referring and referral facility.
- Sample of referral and feedback (counter-referral) letter.

#### **Referral tools**

Standardized referral and feedback (counter-referral) letters are important tools for the referral network (see box opposite). Each time a client is sent to a referral facility, she should be given a referral letter (or a client card) with the reason for referral, all pertinent clinical findings, and her screening test results. If appointments are required, staff at the referring facility should schedule the necessary appointments for the client. Information on the client attending the referral facility (including clinical findings, the results of investigations, any treatment provided, and follow-up recommendations) should be communicated back to the staff who referred her. A functioning communication system (e.g., letters, memos, telephone, fax, periodic staff meetings) should be set up between the facilities to provide feedback to staff and to ensure continuity of care.

#### **Referral Tools**

#### Standardized referral letters

This letter helps to enable continuity of care and should include:

- Name, location, and contact information of the provider and facility referring the client.
- Name, location, and contact information of provider/facility to which client is being referred.
- Client's name, age and/or date of birth, the unique client ID number (if available), facility ID number, laboratory ID number (if applicable), and client's contact information.
- Date, time, and reason for referral.
- Relevant clinical history and findings, results of tests and procedures performed.
- Requests for feedback on client management and advice on follow-up from the staff at the facility to which client was referred.

In addition to documenting referral letters in referral registers, some facilities file carbon copies of referral letters in the client record.

#### Standardized feedback (counter-referral) letter from referral facilities

This letter can be sent from the referral facility back to the original site and should include:

- Name and address of the referral facility.
- Name and address of the facility that originally referred the client.
- Client information (name, age and/or date of birth, contact information), client ID number at the referral, and referring facility numbers (facility numbers can differ).
- Laboratory results and laboratory identification/reference number.
- Date of attendance/non-attendance at the site.
- Findings, management, and follow-up requirements.

#### **Upgrading and organizing referral facilities**

The management team must ensure, through quality assurance site visits, that referral facilities have the capacity to provide the appropriate services for which the client is referred (see Table 6.5). Services should be both client-centered and efficient in terms of the number of providers on staff and their effectiveness. Access to specialized services—such as colposcopy, biopsy, and LEEP—can be increased by providing these services in both secondary and tertiary facilities. Upgrading facilities to provide colposcopy and LEEP requires orienting and training staff in the following areas: counseling, infection prevention, colposcopy, performing LEEP under local anesthesia, recognizing and managing immediate and late complications, and record keeping. It also requires developing and disseminating management protocols and ensuring the availability of equipment and supplies. Staff trained in resuscitation and essential equipment and supplies should be available at referral facilities and facilities providing invasive procedures. Refer to Appendix 6.1 for the list of emergency care equipment and supplies.

# Other linkages

# **Linkages with laboratories**

Linkages between health facilities and laboratories are crucial when the facility is providing screening or treatment that require laboratory processing. Of primary concern are the safe and timely transport of samples and the timely and accurate communication of results.

Programs that provide HPV DNA testing, cytology, or histology must be linked to a reliable laboratory that can process HPV DNA tests, interpret cytology smears, and assess histological specimens. Effective communication between the laboratory and the health facility requires standardized laboratory request forms and report forms (see Appendix 9.3C). Transporting specimens to the laboratories and the collection of results from the laboratories is a major challenge. Health facilities and laboratories often have to use postal or courier services at significant cost. Setting up regular weekly or biweekly transport systems to take tests to the laboratory and to bring results back may be necessary.

It is important to ensure that client registers in both the laboratory and health facility document the vital information required for evaluation and monitoring (see Chapter 9), as this will help provide feedback and improve services. Opportunities to communicate and provide feedback can facilitate assessing and improving the quality of services. In order for this communication and feedback to occur, there must be effective functioning links between the sites. Methods of communication may include letters, telephone, memos, fax, and periodic staff meetings. In addition, a representative of the laboratory staff can be part of the referral task team.

#### Linkages with other health sectors

In countries and settings where there is a scarcity of public-sector pathology and cytology laboratories, it is useful for public-sector management teams to collaborate and coordinate with nongovernmental organizations (NGOs) and private laboratories for these services. Conversely, it would be useful for private and NGO

health services to build and maintain linkages with public-sector facilities, especially at the secondary and tertiary care level, to manage major complications and for cancer treatment services.

#### Linkages with data processing centers

Relevant and correct information collected and documented by service providers at the service delivery sites forms the basis of the HIS. The data is processed to determine the program's efficiency, which in turn enables taking corrective action as required. Timely data collection and periodic feedback requires functioning links between health centers and data processing units. The data collection process is discussed in detail in Chapter 9.

#### Linkages with the community

Trained CHWs, community health volunteers (CHVs), or other outreach workers (community organizers) can play important roles in linking with the community because they are from the community, can locate clients more easily, and can accompany clients to service sites. CHWs can be drawn from the preexisting CHW infrastructure and engaged in various capacities to:

- Inform, educate, or talk about cervical cancer prevention and encourage eligible women to utilize services. (See Chapter 7.)
- Track clients who need treatment or post-treatment follow-up.
- Provide home-based palliative care. (See Chapter 10.)

To enable CHWs to provide appropriate services it is important to train them and provide them with essential job aids, essential supplies, mentoring, supervision, and opportunities to participate in quality improvement activities such as  $COPE^{\circ}$  (see Chapter 10). Periodic meetings with facility staff can assist in strengthening links with the staff at the appropriate facilities. Regardless of the strategy adopted, the complexities involved in establishing and maintaining strong coordination of and communication between individuals and community should not be underestimated.

# **Conclusion**

A prime objective of delivering services is to ensure that precancer screening and treatment services are available and accessible to women. The key steps to achieve this objective are to:

- Provide screening and cryotherapy treatment at all level of health facilities, including appropriate primary health facilities.
- Provide LEEP at referral centers such as selected secondary and all tertiary health facilities.
- Use the single-visit approach (with or without colposcopy) wherever feasible and acceptable.
- Organize a tracking system to ascertain treatment of precancer and to follow up women's post-treatment.
- Organize clinical outreach services using mass campaigns or satellite clinics to increase access for women living in remote or rural areas.

To ensure availability and reliability of services, an efficient supply distribution and logistics chain using local suppliers and a local repair and maintenance service should be in place. In addition, a well-functioning referral network is essential to guarantee continuity of care for women receiving services. Establishing this network will mean setting up a referral task team, developing referral protocols and tools to provide referral services, identifying and upgrading referral facilities, and establishing and maintaining feasible communication systems.

# **Further Reading**

AVSC International. *Emergency Management for the Operating and Recovery Room: Reference Manual.* New York: AVSC International; 2000.

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PATH. *Planning Appropriate Cervical Cancer Prevention Programs*. 2nd ed. Seattle: PATH; 2000.

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WHO and Alliance for Cervical Cancer Prevention (ACCP). Cervical Cancer Prevention in Developing Countries: A Review of Screening and Programmatic Strategies. Geneva: WHO [forthcoming].

WHO. Cytological Screening in the Control of Cervical Cancer: Technical Guidelines. Geneva: WHO; 1988.

# Appendix 6.1. Equipment and Supplies

The following lists include both supplies that are considered essential to performing cervical cancer screening, as well as those that are optimal. Essential supplies and equipment must be procured in order to perform the services at an acceptable level, whereas optimal supplies and equipment are useful but not mandatory.

lies oca	<ul> <li>Cytology: Conventional and Liquid-Based (ytology (LBC)</li> <li>See local norms/recommendations for countries in which a cytology system is in place.</li> <li>Speculum.</li> <li>Speculum.</li> <li>Spatula (wood or plastic).</li> <li>Glass slide (conventional only).</li> <li>Liquid transport medium in individual specimen containers (LBC only).</li> <li>Fixative (conventional only).</li> <li>Cytology request forms.</li> <li>Slide mailers (conventional only).</li> <li>Marker/pencil/glass writer/labels.</li> <li>Record book or sheet.</li> <li>Mechanism for transporting samples to pathologist and back to the health facility or hospital.</li> </ul>
lies alundle of ofe of open open open open open open open open	<ul> <li>Supplies for infection control (see number 11 below).</li> <li>Speculum.</li> <li>Sample collectors (swabs or cervical brushes).</li> <li>Transport medium.</li> <li>Refrigerated storage.</li> <li>Labels.</li> </ul>

Supplies/equipment	Essential	Optimal (Additional or alternative equipment and supplies)
3.VIA	<ul> <li>Supplies for infection control (see number 11 below).</li> <li>Examination table.</li> <li>Vaginal speculum.</li> <li>Clean area for holding sterile/high-level disinfected instruments.</li> <li>3%-5% acetic acid.</li> <li>Light source (torch/flashlight).</li> <li>Large cotton swabs (handmade using cotton batting and orange sticks or ring forceps).</li> <li>Gloves (sterile or nonsterile).</li> <li>Rubber/plastic sheets.</li> <li>Small bowl to hold acetic acid.</li> <li>A screen or a confidential room to provide privacy.</li> </ul>	Alternative  Examination table with stirrups.  Additional  • Metallic vaginal side-wall retractor or condoms.  • 100-watt, focused light source or halogen torch.  • Drape and linen.  • Electrical generator for areas with frequent power outages.  • K-Y jelly.
4.VILI  Lugol's iodine should be labeled and stored in a tightly stoppered brown bottle; it can be stored for up to 1 month.	<ul> <li>Same equipment/supplies as VIA and infection control.</li> <li>Lugol's (potassium iodine) solution (instead of acetic acid solution).</li> </ul>	Same equipment/supplies as VIA and infection control.

Supplies/equipment	Essential	Optimal (Additional or alternative equipment and supplies)
5. Colposcopy	<ul> <li>Same equipment/supplies as for VIA, VILI, and infection control.</li> <li>Colposcope.</li> <li>Normal saline.</li> <li>Endocervical speculum.</li> </ul>	<ul> <li>Additional</li> <li>Voltage regulator/surge protector (for areas with unstable voltage).</li> <li>Generator or car battery and DC-AC inverter (for areas with frequent power outages).</li> </ul>
6. Biopsy and endocervical curettage (ECC)	<ul> <li>Same equipment/supplies as for colposcopy and infection control.</li> <li>Punch biopsy forceps.</li> <li>Formalin.</li> <li>Specimen bottle.</li> <li>Endocervical curette.</li> <li>Monsel's solution (Ferric subsulphate) or silver nitrate sticks.</li> </ul>	<ul> <li>Additional</li> <li>Sponge-holding forceps.</li> <li>Long thumb forceps (toothed and nontoothed).</li> <li>Two small kidney trays.</li> <li>Instrument tray.</li> <li>Instrument trolley.</li> </ul>

Supplies/equipment Esse	Essential	Optimal (Additional or alternative equipment and supplies)
7. Cryotherapy	Same equipment/supplies as for VIA, VILI, colposcopy, and infection control.  Refrigerant gas supply (Cryogen—N <sub>2</sub> O or CO <sub>2</sub> ).  Cryotherapy gun/cryo handset.  Regulator.  Probe tips (shallow conical, 20 and/or 25 mm diameter).  Plastic sleeve.  Rubber stopper.  Flexible hose to connect regulator to cryotherapy unit.  Chain (to secure gas cylinder to wall).  Gas cylinders (keep one for back-up).  Gas cylinder dimensions (see Appendix 6.2).	Same equipment as for VIA, VILI, colposcopy, and infection control.     Antibiotics (available as per national policy guidelines).  Additional     Cryotherapy gas conditioner (a device developed by PATH and currently being field-tested for preventing blocked tubes).

Supplies/equipment	Essential	Optimal (Additional or alternative equipment and supplies)
8. Loop Electrosurgical Excision Procedure (LEEP)	<ul> <li>Same equipment/supplies as for colposcopy and infection control.</li> <li>Electrosurgical generator, electrical cables, electrode holder, other accessories.</li> <li>Grounding pad for client.</li> <li>LEEP electrodes (loops, balls, and needles) for excision and hemostasis.</li> <li>Smoke evacuator.</li> <li>Plastic operating theater suction tip that can be attached to the tubing.</li> <li>For redundant vaginal walls, a new condom that has been slipped over the blades of a vaginal speculum, after which the tip of the condom has been cut off.</li> <li>Local anesthetic solution for injection (preferably containing a vasoconstrictor such a epinephrine/adrenaline or vasopressin).</li> <li>Syringes: one sterile needle (18-20 gauge) for aspiration of local anesthetic and one needle (25-30 gauge) for injection into cervix.</li> <li>Pathology specimen bottles containing formalin for fixation.</li> <li>Monsel's paste) that can be applied easily and adheres well to the excision area. (Monsel's solution bottle should be labeled with the name and date of preparation. Solution can be stored for up to 6 months.).</li> <li>Long-handled needle driver and 0-0 surgical suture material in case of uncontrollable arterial bleeding from excision site, despite decreasing the retraction applied by speculum blades, use of gentle pressure/vaginal pack, application of Monsel's paste, and lastly, use of the macroneedle electrode.</li> </ul>	<ul> <li>Same equipment/supplies as for colposcopy and infection control.</li> <li>Vaginal speculum adapted for the smoke evacuator tubing.</li> <li>Vaginal speculum that has an electrically insulated/nonconductive coating (preferably insulated to avoid shocking client if vaginal walls are touched with the live electrode, but not absolutely required).</li> <li>Dental syringe for local anesthesia.</li> <li>Lateral vaginal walls retractor that is insulated may be needed if the vaginal walls are redundant.</li> <li>Instrument to grasp/retrieve the excised tissue (this could be long thumb forceps or a skin hook).</li> <li>Instrument tray.</li> <li>Trolley or counter top to set instrument tray on.</li> <li>For hemostasis: silver nitrate sticks.</li> </ul>

Supplies/equipment	Essential	Optimal (Additional or alternative equipment and supplies)
9. Knife Cone (cold knife cone)	<ul> <li>Because this procedure is performed under general or regional anesthesia, all supplies necessary for anesthesia should be available.</li> <li>1 vaginal speculum.</li> <li>2 vaginal retractors (double or single end).</li> <li>1 uterine sound.</li> <li>1 uterine dilator (1.5 or 2.0 cm).</li> <li>1 single-toothed tenaculum forceps (9") (vulsellum).</li> <li>1 pointed knife blade (wedge/"beaver blade").</li> <li>1 straight scissors (9").</li> <li>1 curved scissors (9").</li> <li>2 Allis forceps (7.5").</li> <li>2 Allis forceps (7.5").</li> <li>2 chromic catgut sutures #1.</li> <li>3 chromic catgut sutures #1.</li> <li>4 chromic catgut sutures #1.</li> <li>5 chromic catgut sutures #1.</li> <li>6 chromic catgut sutures #1.</li> <li>7 chromic catgut sutures #1.</li> <li>8 Syringe with needle for injecting.</li> <li>6 cotton for cleaning solution (povidone-iodine).</li> <li>6 Gauze.</li> </ul>	<ul> <li>Auvard's speculum (weighted posterior retractor).</li> <li>Additional</li> <li>2 Artery forceps.</li> <li>2 Allis forceps (7.5").</li> <li>2 single-toothed tenaculum forceps (9") (vulsellum).</li> <li>Chromic gut suture includes needle CT 40 mm half-circle.</li> <li>Syringe with long needle.</li> <li>Vasoconstricting agent such as dilute adrenaline or vasopresin.</li> </ul>
10. Counseling (Refer to Appendices 7.1 and 7.2 for lists of counseling materials)		

Supplies/equipment	Essential	Optimal (Additional or alternative equipment and supplies)
11. Infection Control	<ul> <li>Gloves (sterile or nonsterile) for examination.</li> <li>Heavy-duty gloves for handling soiled objects.</li> <li>2 reusable buckets for medical waste disposal (1 for contaminated and 1 for noncontaminated waste).</li> <li>Buckets with lids (prevent chlorine gas escape).</li> <li>Bleach for initial decontamination step (not to exceed 10 minutes to avoid deterioration of instruments).</li> <li>Brushes for mechanical cleaning step.</li> <li>Detergent for mechanical cleaning step.</li> <li>Clean water, sink or basin, fresh water, and soap for rinsing instruments after mechanical cleaning step and washing hands.</li> <li>70%-90% ethyl or isopropyl alcohol wipe (e.g., for cryotip and sleeve).</li> <li>High-level disinfection (0.1% chlorine solution, 2%-4% gluteraldehyde or hydrogen peroxide, adequate facilities for boiling).</li> <li>Cotton, gauze, or clean cloth to decontaminate the examining table surface with bleach after each examination.</li> <li>Sharps disposal containers.</li> <li>Liquid and solid waste disposal—burial pit.</li> <li>Kettle or pot for boiling water.</li> </ul>	Additional  Sterilization (mobile autoclave or dry heat oven).  Protective glasses/goggles and a mask (or face shield).  Clean holding area and containers for sterile/high-level disinfected instruments.  Liquid and solid waste disposal incinerator.  Job aids outlining procedures (wall display).

Supplies/equipment	Essential	Optimal (Additional or alternative equipment and supplies)
12. Equipment and Supplies for Emergency Management  (for referral centers providing LEEP and cold knife cone procedures and centers managing major complications)  Ensure that equipment is placed strategically in the facility close to areas where patients are likely to require resuscitation services.  Develop an emergency kit with drugs for emergency management and emergency equipment and supplies. This kit can be carried to other locations in the facility as necessary.  Conduct periodic rehearsal of emergency responses by having doctors and nurses role-play staged emergencies.	<ul> <li>Blood pressure apparatus.</li> <li>Stethoscope.</li> <li>Infusion sets with large caliber needle (14 or 16 gauge).</li> <li>IV fluids (normal saline and 5% dextrose in water).</li> <li>Hypodermic syringes and needles.</li> <li>Manual resuscitator (Ambu-bag).</li> <li>Face mask.</li> <li>Suction apparatus (manual) with tubing and traps.</li> <li>Nonflexible suction catheter (size 18).</li> <li>Oxygen cylinder with oxygen.</li> <li>Flashlight/torch.</li> <li>Adrenaline.</li> <li>Atropine.</li> <li>Diazepam.</li> <li>Hydrocortisone.</li> <li>Promethazine.</li> <li>Promethazine.</li> </ul>	<ul> <li>Additional</li> <li>Suction apparatus (electrical) with tubing and traps.</li> <li>Flexible suction catheter.</li> <li>Nasopharyngeal airways (size 28 and 30).</li> <li>Lubricant for nasopharyngeal intubation.</li> <li>Foley's catheter.</li> </ul>

# Appendix 6.2. Cryotherapy Refrigerant Tank Size and Number of Procedures

In planning for cryotherapy supply needs, it is important to know how many cryotherapy treatments can be performed with one tank of gas. PATH estimates that 50 six-minute and 30 ten-minute procedures can be performed using an Ascon or Wallach cryotherapy unit, as examples, with a 34 kg (75 lb) cylinder of gas. This estimation may vary depending on the type of cryotherapy unit used, the condition of the unit, the amount of compressed gas remaining in the cylinder, and the climactic conditions. This estimate applies to both carbon dioxide and nitrous oxide. The following table shows the various sizes of pressurized tanks of the two types of refrigerant gases used for cryotherapy, the various characteristics, and the treatment capacity for each type. The prices quoted are based on rates in Kenya.

Cryotherapy r	efrigerant ta	nk size and num	Cryotherapy refrigerant tank size and number of procedures	SI						
	Height	Diameter	Capacity	Cylinder weight (empty)	Gas weight	Total weight (cylinder + gas)	No. of treat- ments per tank	Cost of cylinder for 1 tank* (US\$)	Cost of gas for 1 tank* (US\$)	Total annual cost (US\$)
					Nitrous Oxi	Nitrous Oxide** Lease only.				
Small	46 cm	14 cm	1,800 liters	8 kg	7 kg	15 kg	11	\$5 every month + \$66 deposit	\$35	\$95
Large	150 cm	23 cm	16,560 liters	67–69 kg	31–33 kg	98–102 kg	47–50	\$5 every month + \$66 deposit	\$271	\$331
					Carbon Dioxi	Carbon Dioxide*** Lease only.				
	122 cm	20 cm	34 liters	49–52 kg	23 kg	72–75 kg	35	\$8 every 3 months +\$66 deposit	\$20	\$52

\* A 16% value-added tax applies to Kenya and a similar sales tax may apply to other countries.

<sup>\*\*</sup> Brin's Oxygen Company Ltd.

<sup>\*\*\*</sup> Company Carbacid

# **Appendix 6.3. Checklist for Planning Outreach Clinical Services**

Equipment	Quantity
Cryotherapy equipment including gas cylinder, preferably with wheels	1
Privacy screens	3
Examination table and stools	3
Generator and fuel	1
Instrument tray	3
Clinical supplies	
Specula	25
Sponge forceps	25
Gloves	200
Cotton balls	Approximately 4 per client
Containers (plastic cups) to hold 5% acetic acid (vinegar)	3
Clinical solutions	
5% acetic acid	Approximately 10 ml per client
Monsel's solution	_
Normal saline	_
Other supplies	
Soap	2
Cleaning gloves (utility gloves)	2
Towels	6
Floor cloth and brush (mop)	2
Bleach	_
Halogen light	3
Plastic sheet for examination table	4
Plastic bucket	4
Client records	80
Client ID cards	80
Job aids for counseling (posters and flip charts)	2
Register	In accordance with program protocol

 $<sup>^{\</sup>star}$  Note: This example does not imply that only VIA and cryotherapy can be provided using clinical outreach services.

Example of inventory for a mobile clinic performing screen and treat, using VIA and cryotherapy* Expected workload: 75 women/clinic.		
Pens	12	
Roll of tissue	2	
Timer	2	
Light bulb	6	
Extension plugs	2	
Masterplug multi-socket	2	
Vessel with lid for HLD	1	
Cheatle's forceps	1	
Drum to store instruments	2	
Kerosene stove to boil water	1	
Plastic liners	12	
Waste bin	3	
Medications as appropriate and available		

<sup>\*</sup> Note: This example does not imply that only VIA and cryotherapy can be provided using clinical outreach services.

# **Appendix 6.4. Equipment Illustrations**

# FIGURE 1. Cytology

The specific instruments required to perform cytology are spatulas, slides (preferably with a ground glass end to write client ID), pencils, fixative, and boxes to transport Pap



smears (pictured here). Cytology tests are processed and analyzed in cytology laboratories. Some of the key equipment and supplies needed for this process include microscopes, reagents used for Papanicolau staining, staining dishes with covers, a staining rack, slide trays, and cabinets for archiving slides.

FIGURE 2. HPV DNA test



The specific requirements to perform an HPV DNA test are a brush and a specimen collection bottle containing specified transport medium (pictured here). HPV DNA tests are processed in laboratories and require special equipment including a luminometer integrated with a personal computer and other manufacturer-specific sample preparation and processing equipment and supplies.

FIGURE 3. Examination tray for visual inspection with acetic acid (VIA)



The supplies needed for VIA should be placed on a clean surface (preferably a sterile towel) on a tray or trolley that is readily accessible to the provider. Necessary equipment includes pairs of disposable or reusable, high-level disinfected gloves; cotton applicators for applying normal saline or acetic acid (table

vinegar) to the cervix; a bowl containing dilute 3%–5% acetic acid; a bowl containing normal saline for cleaning the cervix; and a clean holding container for instruments (e.g., speculums).

# **FIGURE 4.** Colposcope

The colposcope is mounted on a stand with wheels. This is a binocular optical device (with a magnification of at least 10 on a basic model) and an adjustable light source that shines on the cervix or other structures being visualized. Fine focus adjustment is usually provided. A green filter improves the contrast of blood vessels. An extra eyepiece permits viewing by a second person and is useful for training, monitoring, and mentoring. To prevent dust accumulation and damage to the lens, it is important to keep the colposcope covered when not in use. The cost of a basic colposcope starts at US\$800; a high-performance colposcope can cost US\$13,000.



# **FIGURE 5.** Colposcopy instrument tray

- 1: Kidney tray
- 2: Bottles with normal saline,5% acetic acid, and Lugol's iodine
- 3: Monsel's solution
- 4: Bottle containing formaline
- 5: Local anesthetic syringe
- 6: Jar containing alcohol for cervical smear fixation
- 7: Cotton-tipped fine swab sticks

- 8: Cervical cytology brushes
- 9: Larger cotton-tipped swab sticks
- 10: Vaginal speculum
- 11: Sponge-holding forceps
- 12: Vaginal side-wall retractor
- 13: Endocervical speculum
- 14: Endocervical curette
- 15: Dissecting forceps
- 16: Punch biopsy forceps



# **FIGURE 6.** Cervical biopsy forceps



Biopsy forceps may be of several different designs, such as Tischler-Morgan, Townsend, or Kevorkian. The shaft of the forceps should be 20 to 25 cm long, so that the instrument reaches the cervix without difficulty, but is not too long to allow the colposcope to be used during biopsy.

It is important that the cutting edges are protected from damage during cleaning and storage, because sharp edges are essential for obtaining a good specimen with as little trauma as possible.

When these instruments are purchased, ensure that a resharpening service is included as part of the cost of the instrument. If this is not possible, organize ways this can be provided locally (e.g., by local jewelers).

# FIGURE 7. Endocervical speculum



This instrument has two small blades that can be inserted into the endocervical canal. It allows visualization of the squamocolumnar junction (SCJ) when parts or all of the SCJ are not visible on routine

examination with the vaginal speculum. The length of this instrument is similar to a cervical biopsy forceps (20 to 25 cm). A long thumb forceps may be used if an endocervical speculum is not available.

# **FIGURE 8.** Cryotherapy apparatus



Cryotherapy equipment consists of a source of refrigerant gas, such as nitrous oxide or carbon dioxide, stored at high pressure in a metal cylinder; a pressure regulator to govern the flow of gas; and tubing that carries the gas to the cryotherapy probe. A basic system will have

a trigger that the operator can depress to allow the gas to circulate through the tubing and the tip of the cryoprobe.

# **FIGURE 9.** Cryoprobes, cryogun, pressure gauge, and stopwatch

Flat cryoprobes or probes with short "nipples" are recommended. It is preferable to have various sizes of cryoprobes. If only one or two cryoprobe sizes are possible, however, then a 20 and/or 25 mm probe is recommended.



# FIGURE 10. Cryotherapy tank

The tank shown is a large-size tank. For safety the tank should be fastened to a wall (e.g., with a chain) to ensure that it cannot fall over and injure someone.

# FIGURE 11. Loop electrosurgical excision procedure (LEEP) equipment

The central functions of the LEEP equipment are generating a high-voltage electrical current and evacuating the smoke generated during the procedure. The electrosurgical generator shown here is incorporated in the same unit as the vacuum source. Lesion excision is done with a hand-held unipolar electrode. Following the excision, coagulation of the remaining surface is achieved with a ball electrode. The patient is elec-

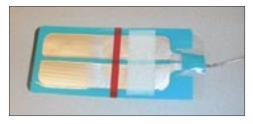


electrode. The patient is electrically grounded by means

of a conductive pad or plate that covers a large surface area of skin and is connected to the electrosurgical generator. For safety reasons, a basic LEEP machine should have circuitry that will sense when an adequate ground connection has not been made with the patient and will not allow the machine to operate. Smoke from the procedure is drawn away through the end of a plastic tube that is placed in the vagina (usually on a specially fitted and insulated vaginal speculum) and connected to a filtered vacuum source. The estimated cost range is US\$3,500 to US\$5,000.



#### FIGURE 12. Grounding pad for LEEP



In order for LEEP to be conducted safely, a electrical ground connection must be made between the patient and the electrosurgical generator unit to allow the electricity to return to its source. This picture shows a disposable adhesive pad that has approximately a 15 x 20 cm metal surface

area that is in contact with a patient's outer thigh during LEEP. Another style of ground pad is a stainless steel sheet of at least the same dimensions that is coated with a special conductive lubricant and is placed against the patient's skin in the lower back. In contrast to the disposable, adhesive ground pad, this type of metal plate is reusable and is a common piece of electrocautery equipment used in many operating theaters. Connection with the electrosurgical generator device is made by a wire that connects to the ground pad or plate.

## FIGURE 13. Instrument tray for LEEP

- 1: Kidney tray
- 2: Bottles with normal saline,5% acetic acid, and Lugol's iodine
- 3: Monsel's solution
- 4: Bottle containing formalin
- 5: Bottle containing local anaesthetic agent
- 6: Syringe for local anesthesia
- 7: Needle and suture material
- 8: Loops and ball electrode

- 9: Patient return electrode or dispersive plate
- 10: Pencil with the hand switch
- 11: Cotton swabs
- 12: Insulated vaginal speculum
- 13: Sponge-holding forceps
- 14: Insulated vaginal side-wall retractor
- 15: Dissecting forceps
- 16: Endocervical curette

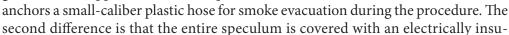


#### **FIGURE 14.** LEEP electrodes and loops

Ball electrode, macroneedle-style electrode, and various sizes of loops

#### FIGURE 15. Insulated vaginal speculum for LEEP

A specially constructed metal speculum is used for LEEP. The first feature to note is the metal guide on the upper blade of the speculum that





lating coating. This insulating layer guards against inadvertently shocking a patient during LEEP if the wire loop electrode accidentally touches the speculum. This speculum is more expensive and must be handled with extra care when cleaning, disinfecting, and storing since the special coating wears off with rough handling.

#### FIGURE 16. High-level disinfection: a boiling water bath

After instruments such as vaginal specula and biopsy forceps are decontaminated for 10 minutes in a dilute bleach solution and then mechanically cleaned with detergent and rinsed with clean water, high-level disinfection can be performed to make them safe for use. One of the simplest methods is to boil the instruments for at least 20 minutes in a bath of tap water. Water in the bath should be changed daily and the vessel should be washed and stored dry.



**FIGURE 17.** Autoclave: high-pressure, saturated steam sterilization



Instead of using a boiling water bath for high-level disinfection, this method ensures an even higher degree of cleanliness, called sterilization. An autoclave achieves high pressure and high temperature, and usually 30 minutes are adequate exposure (manufacturer's recommendations should be followed). This autoclave is portable and is heated by an electric or gas burner.

#### FIGURE 18. Telecobalt machine

The radioactive source (cobalt) is kept in a lead container in the head of the machine, from which radiation is directed to the tumor site through an outlet. The head of the machine can be rotated around the patient who lies on a couch so that the radiation beam can be directed in different angles. Cost of the equipment is about US\$350,000. Due to radioactive decay, the source needs to be changed every 7 years.



7

#### 7

# Providing Information and Counseling to Address Community and Client Needs

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## **Key Messages**

- To increase use of cervical cancer prevention services, an information and education (I&E) plan that considers a combination of community-, facility-, and media-based strategies should be implemented to inform women in the target age group and their partners about the benefits and availability of cervical cancer prevention services.
- Strategies to increase program coverage rates that utilize a community
  focus include listening to and learning from the community, involving
  community stakeholders in program development and implementation,
  and responding in ways that address community needs through materials development, outreach activities, and local action planning.
- Information and education strategies should be directed toward women
  who have never been screened before and toward their partners and
  family members who can encourage them to solicit screening and
  comply with follow-up instructions.
- Direct contact with health workers and peer educators, such as satisfied clients, is often more effective in increasing use of services than short-term media activities.
- Group awareness raising, followed by individual counseling, will address clients' information and emotional needs, motivate them to follow treatment recommendations, and establish a satisfied clientele who will encourage other women to attend.
- Printed materials are helpful aids for education and counseling (if resources to make and reprint them are available), but they should not replace direct provider contact.

#### Introduction

Client access to screening and treatment services is essential to ensure the success of a cervical cancer prevention program; however, the mere availability of services is insufficient to guarantee their use. In addition, clients and community members must be aware of the problem of cervical cancer, their potential risk of developing the illness, and the facilities where they can solicit screening services. Well-designed, strategically targeted I&E efforts can motivate women to access prevention services.\* Women who do seek prevention services should then be counseled and provided with information and emotional support, and health care providers should ensure that clients' rights are protected.

<sup>\*</sup> In some settings, strategies to inform and educate the public about health services are called "Information, Education, and Communications" (IEC). In other settings, similar strategies are referred to as "Behavior Change Communications" (BCC). To avoid confusion, this manual uses the term "Information and Education" (I&E), leaving it to the readers to use whichever term is appropriate in their settings.

Providing accessible and affordable services and actively promoting them to the target population can significantly increase the use of services and reduce cervical cancer incidence. Other barriers, however, may discourage women from soliciting such available services (see box below). Lack of awareness about the disease and its prevention, embarrassment or shame about having a pelvic exam, as well as fear of the screening procedure, fear of cancer, and common misconceptions, can negatively affect the use of cervical cancer prevention services (Ajayi and Adewole 1998, Fylan 1998, Bingham et al. 2003, EngenderHealth 2003b, Agurto et al. 2004, Bolivia Ministry of Health et al. 2003). For those who do access services, the care provided may not always address women's needs nor support their basic rights, including the right to information, the right to make voluntary and informed decisions, and the right to confidentiality. Clients are more satisfied and more likely to use services and comply with follow-up when they are treated with dignity and respect and when providers take the time to converse with them, answer questions, explain procedures, and give encouragement (Lazcano-Ponce et al. 1999).

#### Clients' Barriers and Perceptions of Services: South Africa

EngenderHealth collaborated with the University of Cape Town (South Africa) to conduct qualitative research with more than 200 women in Khayelitsha, an informal settlement on the outskirts of Cape Town. They found that it was difficult for women to decide to go for screening because it was stressful, because of prior unsatisfactory experiences with health services, cultural taboos, and the influence of male opinions about pelvic examinations.

- Fear was commonly reported by women who contemplated screening—not fear associated with the procedure per se, or even fear of possibly finding out they had cancer, but fear of challenging cultural taboos against exposing their genitals and fear of challenging their sex partner's control over them.
- Knowledge of cervical screening was not a sufficient motivating factor for most women to seek screening. In fact, most women came for screening because they were ill or perceived themselves to be ill (illnesses that were usually unrelated to cervical cancer) and had heard that they would receive respectful care.

Those who did attend reported that screening and treatment with cryotherapy were highly acceptable, their experiences with services were positive, and that they would recommend that friends and relatives attend.

Source: EngenderHealth 2003b.

## The Role of the Management Team

By ensuring that I&E strategies and counseling address women's cultural, emotional, and practical needs and concerns, and by promoting positive client-provider relationships, the management team can significantly impact the uptake of services, improve follow-up rates, and enhance the program's success. The management team's four key responsibilities in implementing I&E services are to:

- Develop an I&E plan that considers community-, facility-, and mediabased strategies to provide appropriate information to women who are eligible for screening and to their partners.
- Build support from stakeholders, especially community leaders and client representatives.
- Ensure that trained staff provide counseling to clients to support informed decision-making.
- Ensure the availability of educational materials that are culturally appropriate, accurate, and consistent.
- Monitor and evaluate the effectiveness of the various I&E strategies and make changes as necessary.

## **Developing a Plan to Reach Eligible Women**

## **Objectives and challenges**

Evidence from countries with screening programs shows that more than 50% of women diagnosed with cervical cancer have never been screened. Thus, one fundamental goal of a cervical cancer prevention program is to increase the use of screening services. To satisfy that goal and increase the program's effectiveness, one has to focus on women in the target age group who have not been screened in a given time period.

Many women who frequent health care facilities are never screened for cervical cancer. According to one study in the United States, the majority of women diagnosed with cervical cancer had seen a doctor during the three years prior to diagnosis, but had not been screened for cervical cancer (Kinney et al. 1998). For that reason, it is important to incorporate a facility-based strategy into the plan to encourage women to utilize screening services.

## Reaching medically underserved women

Within the population of women who have never been screened, one of the greatest challenges is to reach women who do not normally access health services. These medically "underserved" women are difficult to involve in routine promotional strategies. Understanding the characteristics of underserved women and the underlying factors that hinder their participation will assist in designing appropriate I&E strategies that increase their use of cervical cancer prevention services.

In many cultures, people are not oriented to preventive care and seek medical attention only when there is a perceived need or symptomatic problem. Furthermore,

impoverished women with families tend not to prioritize their own health, and instead, they direct scarce resources to preserve the health and well-being of their partners and children. In many societies, men are the primary decision-makers in the family, and women are required to request their permission to seek medical care. Women may also be medically underserved due to economic factors (cost of services or inability to forgo earnings to use services), geography (living in remote areas or in temporary dwellings with frequent relocation), or lack of transport. Some women choose not to attend health facilities because of a previous negative experience, concerns about privacy or confidentiality, cultural beliefs or traditions, or misinformation about the purpose and availability of services. Hard-to-reach women also include those who are marginalized by society, such as ethnic minorities, sex workers, intravenous drug users, and women known or thought to be infected with HIV (WHO and ACCP forthcoming).

To design the best strategies for reaching women who do not traditionally use services, it is important to identify the factors that can affect participation in screening programs. These include (Bingham et al. 2003):

- Accessibility (proximity of facility, conveniently scheduled service hours).
- Coordination between communication agents and health facilities.
- Collaboration between health facilities and community women's groups.
- Functioning community advisory groups.
- Support of health service directors.
- Promotion by word of mouth (satisfied clients).

## **Components of an Information and Education Plan**

The ACCP's experience supports the idea that proactive efforts to focus on the community are vital to increase attendance by eligible women at cervical cancer prevention services. Strategies to increase coverage rates that utilize a community focus include:

- Listening to and learning from the community by understanding cultural perceptions about cervical cancer, barriers to screening participation, and characteristics of underserved women, and using continuous quality improvement processes.
- Involving community stakeholders such as local organizations, community advisory groups, CHWs, and men in program development and implementation.
- Responding in ways that address the needs of the community through communication materials, outreach activities, and local action planning.

These strategies are designed to increase and sustain demand and improve the quality of services, resulting in increased participation in screening and compliance with treatment recommendations (ACCP 2004b).

The management team is responsible for developing a locally appropriate I&E plan to reach women in the target age group and to provide information about cervical cancer prevention and services. The plan should target specific audience(s) and use a combination of I&E strategies. It should outline a strategy for identifying, training, and supporting the most effective communication agents. It should also include developing or adapting print or media materials about cervical cancer and its prevention that are understandable, culturally appropriate, and motivating.

Table 7.1 lists potential informational activities, possible individuals who can effectively provide information, and appropriate venues for informing women, their partners, and the community in general. This list is not exhaustive; many other activities and locations are possible, and not all the ideas listed will work in all situations. The management team should select the strategies that best suit their situation, particularly those that have been effective in the past.

**TABLE 7.1.** How, by whom, and where to communicate with women and their partners

Approaches for providing information	Communication agents	Locations
<ul> <li>Direct personal contact</li> <li>Community health meetings</li> <li>Posters or pamphlets</li> <li>Women's journals or periodicals</li> <li>Puppet shows</li> <li>Stage plays (dramas)</li> <li>Photo comics</li> <li>Newspaper advertisements or articles</li> <li>Radio messages</li> <li>Television dramas, public service announcements</li> <li>Telephone hotlines</li> <li>Internet web site</li> </ul>	<ul> <li>Peers (i.e., people of same age and social group as potential clients)</li> <li>Traditional healers</li> <li>Leaders and members of women's groups</li> <li>Community health workers</li> <li>Community health volunteers</li> <li>Religious leaders</li> <li>Community leaders</li> <li>Midwives</li> <li>Nurses</li> <li>Medical social workers</li> <li>Doctors</li> </ul>	<ul> <li>Homes</li> <li>Women's groups or community centers</li> <li>Workplace or market</li> <li>Places of worship</li> <li>Family planning or reproductive health centers</li> <li>Hospitals</li> <li>Local festivals</li> </ul>

Source: Adapted from WHO and ACCP forthcoming.

## **Information and Education Strategies**

Three basic types of I&E strategies are:

- *Community-based* (outreach): one-on-one and group activities to inform people in homes and community settings.
- *Facility-based* (inreach): one-on-one and group activities to inform patients who are attending health facilities.
- *Media-based:* radio, television, and print media to convey messages to a larger and more dispersed audience.

The strategies used must be culturally specific and tailored to each community.

For example, in countries with a tradition of village health workers and house-to-house censuses, it may be possible to determine who has been previously screened. In such cases, the health worker can systematically contact those women in the target age group who require immediate screening.

When deciding on I&E strategies, it is important to consider the economic feasibility and cost implications before proceeding with the activities. Some approaches, such as using mass media, can be more expensive, and therefore it is advisable to do a cost-benefit analysis before investing limited funds.

## **Involving Community Leaders**

Regardless of the I&E strategies used, the management team is responsible for involving community leaders and other stakeholders in designing and supporting the I&E plan, and for ensuring consistency in the messages conveyed. When developing the I&E plan, members of the management team should meet with community leaders, traditional healers, and women's groups, brief them about cervical cancer prevention and the proposed strategies, request their input, and solicit their endorsement and commitment to the program. Establishing and maintaining an open dialogue with representatives from community groups is vital to the acceptance and sustainability of the cervical cancer prevention program, particularly in communities where use of traditional healers and natural medicine are common.

## **Feedback Between Strategies and Outcomes**

Periodic evaluations must be incorporated in the I&E plan to ensure that the selected I&E strategies result in higher coverage rates and lower attrition rates. By monitoring outcomes, the management team can recognize those I&E interventions that are successful and those that require modification. Assessment indicators can be selected from information provided in the clinic registers. (See Chapter 9.)

## **Outreach: Community-Based Information and Education**

## Using community health workers and volunteers

Community outreach—community-based I&E activities—is an effective way of informing eligible women about the importance and availability of cervical cancer screening. Many health systems use trained CHWs, volunteers, and peer educators to inform community members about disease and prevention, and to promote available health services. Because they reside in the same communities and have similar lifestyles as women in the target population, CHWs are often able to establish a good rapport more easily than providers can in a clinic setting. In many cases, these health workers require only information updates about cervical cancer prevention in order to incorporate the topic into their existing and ongoing outreach work.

Learning about cervical cancer and its prevention from a person who has already undergone the experience of screening or treatment can have a big influence on decisionmaking and ultimately on behavior change. ACCP experience demonstrates that much information about cervical cancer prevention spreads by word of mouth. Women are often persuaded to undergo screening by rel-



Community theater is an effective strategy for public education about cervical cancer prevention.

atives, friends, and neighbors who have already done so themselves. An I&E plan can utilize these social networks for outreach purposes by encouraging every woman who has been screened to refer five of her family or friends for screening. In addition, family members, neighbors, and community members who have previously used services could accompany women who are hesitant and fearful of attending on their own.

#### **Outreach activities**

Besides direct contact with a community worker, examples of community outreach activities include:

- Community health education. Organized information sessions provided by trained CHWs can increase utilization of cervical cancer prevention services. Table 7.1 lists possible locations for delivering health education in the community.
- Home visits. During visits in the home, CHWs can provide information
  about prevention services, address concerns and questions, and assist
  women in making arrangements to attend the health facility. If a male
  partner or other family members are present, they can be included in
  the discussion.
- Reaching out to social and family networks. Satisfied clients can advocate for cervical cancer screening to their friends and family members.
- *Involving men*. Male peer educators can mobilize other men to encourage the women in their lives to participate in cervical cancer screening. Partner support is particularly important for clients undergoing treatment of precancer, so that they can comply with the requirement of four weeks of sexual abstinence following treatment.
- Tapping into cultural norms and traditions. Culturally appropriate plays, puppet shows, community fairs, or carnivals with performances by local artists can be organized to present issues related to cervical cancer prevention (see next box).

## Protecting the Health of "Goddesses of Wealth": Encouraging Women to Solicit Screening Services in Barshi, India

As part of a health education program used by IARC in Barshi, India, a video of a short drama, "Dear Lady, You Are the Goddess of Wealth in Your Home," was produced. The video was shown to community members in each village the night before mobile detection activities were scheduled. The dialogue in the video is in the local language, Marathi, and tells the story of a concerned woman and her mother who is unwilling to get screened for cervical cancer. After being urged by her daughter and the daughter of a neighbor whose mother had died of cervical cancer, she is finally convinced and agrees to get screened. The story conveys the message that women are highly valued members of a household and can be protected from developing cervical cancer. The video was shown in more than 300 villages where mobile screening services were provided.

Most cervical cancer prevention programs implement a combination of two or more community outreach activities to diversify efforts and broaden the audience. For example, the ACCP project in Peru combined community health education, home visits, and peer education in its attempts to recruit as many eligible women as possible to use screening services for the first time (see box below).

#### **Recruiting Clients Through Community Participation in Peru**

In Peru, ACCP partners implemented a participatory client recruitment process to increase utilization of cervical cancer prevention services. Two principal components characterized this sustainable model: (1) provide women with education and information to enable them to make informed decisions about cervical cancer prevention and demand high-quality services, and (2) ensure that women who receive prevention services are satisfied and encourage other women to attend.

The first strategy component required shared responsibility between health personnel and community members. Eighty promotion teams with one health care staff member and one community leader were formed to hold awareness-raising meetings on cervical cancer prevention; lead education sessions on the topics of "knowing my body," vaginal infections, cervical cancer, and self-esteem; and perform home visits to women who had been screened and did not return to the health center for clinical follow-up.



The second component recognized the impact that quality has on service uptake, and the effect that satisfied clients have on promoting quality services. To ensure that women received quality services, providers participated in a continuous quality-improvement process to identify solutions for problem areas. In turn, satisfied clients would be more likely to promote the cervical cancer prevention services to the women in their social and family networks.

## **Developing Local Partnerships**

The importance of establishing close links and partnerships with other health, social, and cultural institutions and community organizations cannot be stressed enough. Such linkages are crucial in increasing screening coverage of eligible women. They also enable the provision of comprehensive services that address women's needs. Examples of individuals or organizations with whom partnerships for outreach can be developed include:

- *Traditional healers*. Partnering with traditional healers can help to reassure community members who may be skeptical of a "modern" medical facility, and therefore encourage client participation.
- Nongovernmental organizations (NGOs). Partnerships with local organizations facilitate referrals for emotional and spiritual support, as well as for clinical services. Religious and other community groups may have trained social workers, counselors, and support groups to respond to women's needs (see box on page 136). This is particularly important for women who have been diagnosed with cervical precancer or cancer.
- Local assistance programs. Financial assistance and subsidies may be available for clients to ease the economic burden of prevention and treatment procedures. Securing funds to defray costs of treatment or housing for women and their families who must travel from remote areas for care will encourage women to follow through with treatment and management recommendations (ACCP 2004c).

#### Partnering With a Women's Organization in Kenya

This ACCP project in Kenya partnered with the Maendeleo Ya Wanawake Organization (MYWO), a national grassroots women's organization with an estimated membership of 2 million individuals and more than 25,000 women's groups. Thirty-five members in the project area volunteered to conduct outreach to women in the community to motivate them to seek screening services. Group-based approaches employed included addressing women's groups, religious groups, school-based parent groups, and *barazas* (local meetings of village elders and local administrators to discuss community issues). Individual home visits were also organized to allow women to discuss personal concerns or questions.

## **Facility-Based Information and Education**

Facility-based I&E is an organized effort to inform facility users and staff about cervical cancer prevention and to increase in-house referrals. Sometimes referred to as "inreach," this strategy uses resources *within* a health facility to inform clients, visitors, and other staff about cervical cancer prevention and the availability of services for women in the target population. Facility-based I&E activities also seek to improve client referrals among services provided at the facility.

Whereas community outreach can successfully motivate women who do not routinely use health services, the ACCP has found that many women who do seek care at clinics and hospitals have never been screened for cervical cancer. In countries where the screening coverage is low, and therefore cervical precancer and cancer prevalence is likely to be high, coverage can be expanded by screening eligible women who are easiest to find—those presenting to clinics. Clients typically solicit health care for a specific problem and providers generally respond to that problem, missing the opportunity to identify and address other health needs. "Missed opportunities" are especially relevant for cervical cancer prevention. Clients, community members, and providers themselves often report that health staff do not discuss cervical cancer prevention with women who attend for non-reproductive health reasons.

The management team is responsible for ensuring the coordination of a number of activities for a comprehensive inreach strategy, including:

- Health talks. Often, talks on important health issues are presented to people in the facility waiting rooms, and it is simple to incorporate key messages about cervical cancer prevention. Materials to complement group awareness-raising sessions include videos and flip charts (see Appendix 7.1 or visit www.alliance-cxca.org).
- Signs and posters. Key messages can be conveyed quickly to clients in waiting rooms, restrooms, and examination rooms through welldesigned posters.

- Orientation sessions for all staff. Not only doctors, but all staff should have information on cervical cancer prevention services, including where and when they are available.
- Referrals from other health services. Providers of services used by women in the target age group—such as general outpatient clinics, hypertension clinics, and diabetic clinics—should routinely ask every woman they examine if she has ever been screened and when, and should refer them appropriately.

#### **Media-Based Information and Education**

Mass media can bring education to people in their own homes without interfering with their home-based tasks, which often prevent women from participating in community health education programs (Samuels et al. 1996). For that reason, mass media can play an important role in encouraging the use of effective services and in discouraging those of unproven effectiveness (Grilli et al. 2002).

Using mass media for cervical cancer prevention can include running public service announcements on radio and television; advertising in newspapers and magazines, and on the Internet (where available and feasible); publicizing services on local radio and TV talk shows; displaying posters; distributing pamphlets; and developing documentaries for television and radio. In many countries, health topics are presented on the radio to influence the behavior of both health professionals and potential clients. Nevertheless, it is important to keep in mind that using mass media requires specialized skills and equipment, and costs (per person screened) can be high (Risi et al. 2004).

Key points to consider when using radio or television:

- Use local radio networks or community radio to save time and money.
- Use free air time (public service announcements).
- Determine the time slots that will best reach the target audience (women over the age of 30 years).
- Develop advertisements for service sites and times that precede or follow related radio or television broadcasts.
- Engage celebrities (actors, actresses, sports personalities, popular singers, and entertainers) to convey messages and to be "champions" for cervical cancer prevention.
- Ensure that key messages are consistent with program objectives. (See page 145 for suggested key messages.)
- Determine whether TV and radio are appropriate means of communication to the intended audience. For example, is there a constant electricity supply? Do most homes have TV and/or radio?
- Obtain cost estimates and determine whether the anticipated outcome justifies the expense, which is likely to be higher than for other approaches (see box on next page).

## The Impact of Media Campaigns on Uptake of Cervical Screening in South Africa

Before investing in an expensive mass media effort, it is advisable to weigh the potential impact of the intervention against the required inputs. The effect of a mass media intervention and a targeted education intervention on cervical screening uptake was evaluated in South Africa. *Nokhwezi's Story*, a health education photo comic that addressed the issue of cervical cancer and its prevention, and a "control" photo comic were distributed to a randomly selected population of 658 women (35 to 65 years old). One month later, a radio drama based on the storyline presented in the photo comic was broadcast over the community radio station.

Six months following the distribution of the photo comic and the airing of the radio play, the study participants were surveyed for self-reported uptake of cervical cancer screening. The radio drama demonstrated a positive effect on cervical screening uptake, however that impact was lessened by limited audience exposure. The women who could recall key information from the photo comic or radio drama were more likely to have reported having a Pap test, but even so, the overall screening rate was quite low—approximately 6.5%. One conclusion that the researchers drew from this study was that limited financial and human resources would be better targeted toward personalized one-on-one activities rather than toward expensive, large-scale, short-term, mass media activities.

Source: Risi et al. 2004.

## **Counseling**

Meeting clients' informational needs should not cease once a woman decides to obtain screening services. In fact, she (and her partner) will likely have more questions and concerns and require more information. Personal, individualized communication between a woman and her provider greatly enhances client satisfaction and is a critical dimension of quality of care. Women are more likely to seek services from health workers who are sensitive and responsive to their needs. A woman who is treated poorly is less likely to return for follow-up and may share her negative experience with others, who will then be discouraged from attending.

Counseling is defined as two-way communication between a client and a health worker to identify and address the client's needs and concerns (see box opposite). It is considered an essential element of screening and diagnostic and/or treatment services. The management team should ensure that all site staff understand the importance of counseling and their role in providing it, that they are trained in communication skills and counseling, and that they have the time, space, and resources needed to effectively counsel each client.

## **Objectives of counseling**

Counseling should be provided to all clients to achieve the following:

- Confirm that the client is eligible for screening (according to national or facility guidelines).
- Use clear and simple messages to inform the client about cervical precancer and cancer, the significance of prevention, and screening and treatment procedures, so that she can make an informed decision.
- Explain the importance of follow-up, either for management of precancerous conditions or for future screening, and compliance with post-treatment instructions.
- Help the client overcome her anxieties and fears related to the disease, screening, and treatment by encouraging her to express her concerns, listening, responding to her questions, clarifying any misconceptions, and providing reassurance.

#### **Key Definitions**

*Counseling*: Two-way communication between a client and provider to identify and address the client's needs and concerns.

*Informed decision-making*: Voluntary decisions based on an understanding of information presented and available options.

*Informed consent:* Verbal or written communication from the client to the provider that confirms that the client understands and chooses to undergo a given procedure.

## Clients' rights

Counseling plays an important role in protecting four of the seven categories of client's rights described in Chapter 3: the rights to complete and accurate information; informed decision-making; privacy and confidentiality; and dignity, comfort, and expression of opinion.

#### The clients' right to information

The right to information is widely recognized as a fundamental client right in all health services (Huezo and Carignan 1997). Providers tend to not want to overburden clients with unnecessary details, but the amount of information that women actually want when receiving care is often underestimated (Marteau 1990). Giving women comprehensive information will enhance their likelihood of complying with follow-up instructions, treatment protocols, and continuation of prevention

behaviors (ACCP 2003). As noted earlier, satisfied clients are often the most effective promoters of program services. Thus, the investment in addressing women's information needs, when combined with the availability of appropriate services, will strengthen the program's impact.

#### The clients' right to make informed and voluntary decisions

Counseling is a crucial tool to enable and support clients to make autonomous decisions without coercion, a fundamental human right of reproductive health clients (United Nations 1995). Examples of decisions that women make concerning their cervical health include whether to:

- Seek information.
- Undergo screening.
- Retrieve screening results.
- Adhere to management recommendations and seek follow-up tests or treatment if screening results are positive.

Individual counseling is essential to addressing clients' needs, motivating them to follow treatment recommendations, and establishing a satisfied clientele.

- Inform their partners about the decision to get screened and, if necessary, receive treatment.
- Comply with the recommendation to delay sexual intercourse for four weeks following cryotherapy treatment.

Informed consent indicates that a client has received and understood the information about a given procedure and has made an informed decision to undergo the procedure. Informed consent should be a required outcome of counseling for cervical cancer screening and treatment procedures and may be given verbally or documented in writing, depending on policies of the health care system. The process for obtaining informed consent and the contents of a printed form should also be based on standard medical practice in the respective countries.

#### The clients' right to confidentiality

Any health service must be established so that clients' personal and clinical information is handled with total discretion. Client names and diagnoses should not be discussed publicly, and client records should be made available only to service providers and carefully secured when not in use. Disregard for the clients' right to confidentiality could have negative effects for clients outside the health care facility, as well as for the reputation of the service site.

#### The clients' right to dignity, comfort, and expression of opinion

One of the barriers mentioned previously that make some women reluctant to access screening services is the embarrassment and shame associated with having a pelvic examination. By asking about women's needs and feelings during counseling, as well as during clinical procedures, service providers can reassure clients that their opinions and concerns are respected, even if the situation does not allow

total comfort or privacy. Service providers can help to minimize embarrassment by making efforts to ensure women's dignity during examination, for example, by placing screens or curtains around the examination table and providing gowns that adequately cover women's genitals while awaiting screening procedures.

#### Who can or should provide counseling?

The appropriate person(s) to provide counseling varies according to the site or health system and available personnel. Very few facilities have designated "counselors" on staff. Instead, a range of staff, such as doctors, nurses, nurse auxiliaries, social workers, and even volunteers, are used for counseling. Any staff member who is sensitive to clients' needs can provide effective counseling, as long as he or she has accurate and updated information and has been trained in basic counseling techniques.

When a woman comes to a clinic, she may meet and interact with many people, including receptionists, security guards, nurses, doctors, social workers, and janitorial staff. Although such interaction cannot be a substitute for counseling, all these people can and do provide women with information about cervical cancer prevention and where to solicit screening services. It is important to consider the potential impact that all staff may have on a woman from the moment she walks into the clinic and to design orientation programs that maximize their positive impact on clients' decision-making and comfort.

#### **Factors influencing counseling**

Even when counseling is provided, it often does not meet clients' information and emotional needs for a variety of reasons. The management team must address providers' concerns and the potential obstacles that inhibit them from effectively and routinely providing counseling to clients (see box below). The management team is responsible for ensuring that providers are adequately trained, that scheduling allows sufficient time for quality client-provider interaction, and that facilities are able to ensure visual and auditory privacy.

#### **Common Barriers to Counseling**

Barriers that health workers report include:

- Insufficient time to properly counsel clients.
- Inadequate space to ensure privacy and confidentiality during counseling.
- Embarrassment about raising sensitive issues with clients.
- Lack of awareness of clients' questions and concerns.

Important elements that the management team should address with staff, incorporate into counseling services, and reinforce through trainings and workshops are:

- Client-centered, one-on-one counseling. Women are generally reluctant to ask personal questions openly during group health talks. One-on-one counseling should be provided to each woman seeking services to allow them to ask such questions, and should be client-centered, meaning that each client is considered as an individual and the counseling is adapted to address her specific needs. At a minimum, counseling should be conducted in a language that a woman understands, preferably her primary language. Ideally, counseling should occur before and after each procedure to reinforce key messages and to address any new concerns.
- *Inclusion of partners*. Women's partners should be encouraged to participate in counseling as well, especially partners of women who need treatment. Men can play a significant role in supporting women's health, but can only do so if they have the necessary information. It is important, however, to respect a woman's need for privacy as she might have health concerns that she would not wish to discuss in the presence of her partner.
- Provider knowledge. Clients need to feel that providers are knowledgeable and can answer their questions. Health workers should be able to discuss the basics of the natural history of cervical cancer and its prevention, diagnosis, and treatment, using words that clients can easily understand.
- Counseling skills. It is every provider's responsibility to incorporate counseling in her or his interactions with clients, both before screening and treatment procedures and after. Therefore, every provider must develop general counseling skills to improve communication and efficiency, overcome embarrassment about discussing sexuality and cancer, raise awareness of clients' common concerns, and become more sensitive to clients' feelings and experiences. The management team can provide training and ongoing supervision to reinforce the application of skills (see Chapter 8).
- *Privacy.* A private atmosphere that honors a client's confidentiality is essential when trying to create open and honest communication and to convey respect. Although desirable, a separate room for counseling is not necessary, as long as there is visual and auditory privacy, with limited interruptions and a minimum of people using the space.
- Maximizing time for individual counseling through "group counseling." Providers often complain that heavy caseloads result in insufficient time for counseling. For increased efficiency, general information can be provided to many women during group awareness raising sessions while they are waiting to see a doctor. The individual counseling that follows can then focus more on reinforcing key messages from the health talk and answering the client's personal questions.

#### **Information and Education Materials**

#### **Developing versus adapting printed materials**

The combined use of interactive counseling and written or illustrated materials will ensure that the provider covers all the necessary information, that information is better absorbed by the client, and that clients have something to refer to in case they forget the details presented. Leaflets, flip charts, and photo comics can be used both as job aids and as client education materials.

The management team should use caution, however, when planning and developing printed materials; they can be expensive and time-consuming, as the many steps described in the box on the next page indicate. Also, unless funding is available for reprinting, supplies can be quickly exhausted and then never replenished. As an alternative, existing materials may be adapted to meet the specific needs of a target population. Once materials are finalized, photocopying can be much easier and more economical than formal printing. The ACCP has developed numerous fact sheets, flip charts, and other materials that can be adapted to local needs (they are listed in Appendix 7.1). As with developing new materials, the steps for adapting text and illustrations are similar: identify the target audience and ensure through pretesting that the materials are intelligible and relevant to that audience.

## **Eight Steps to Effective Materials Development**

- 1. Plan your project.
  - Review existing materials.
  - Define objectives.
  - Create a work plan.
  - Develop a budget.
- 2. Identify and study your audience.
  - Define your target audience.
  - Research their information needs, language preferences, reading levels.
- 3. Develop key messages.
- 4. Create draft materials (combining text and pictures).
- 5. Pretest and revise draft materials.
  - Have users of materials review and provide feedback on the materials and suggest changes.
  - Revise materials based on their comments.
- 6. Produce materials.
- 7. Distribute materials and train staff in their use.
- 8. Evaluate materials.
  - Interview users about distribution, comprehension, and acceptability.

Source: PATH 2001.

#### Key messages for women and their partners

#### General information about cervical cancer prevention

Many people use health services for curative purposes only and are not accustomed to seeking care when they are asymptomatic. Thus, it is necessary to address the concept of prevention as a health care strategy. Before a client makes the decision to undergo cervical screening, it is important that she receive basic information about the natural history of cervical cancer and the severity of disease in order to better understand how screening and treatment of precancer can benefit her and those who depend on her. It is helpful to explain the relative ease and economy with which women can be screened, particularly when it results in early intervention.

#### Information about cervical cancer screening and diagnosis

Before a woman undergoes screening, it is important that she understand what the procedure entails and the steps that will be taken if an abnormality is detected. Demonstrating what happens during the screening procedure and showing women the instruments used is particularly helpful to dispel myths and to alleviate anxiety.

#### Information about screening results

Before talking to women about their options for treatment of precancer, it is necessary to make sure that they understand the meaning of their results. Women often experience great anxiety around a positive result because they are worried that it means they have cancer and will die. *Providers and program staff should understand* that the categories of results differ according to the test used (cytology, HPV DNA test, visual test), and that I&E materials should be specific for the particular tests used.

#### Information about treatment for precancer

Women can be reluctant to undergo treatment for precancerous conditions because they do not have the information they need to make an informed decision. For this reason, the provider or counselor must make sure that their clients have the support necessary to make well-informed decisions regarding the management of any detected lesions. It is essential that women who undergo treatment for precancer comply with follow-up recommendations after they receive treatment. It is often challenging for women to heed post-treatment sexual abstinence recommendations due to the dynamics of the relationships with their partners, and this highlights the need for effective partner education. Furthermore, women who are lost to follow-up endanger their health by discontinuing contact with their health care providers.

#### **Conclusion**

Before women and other community members can willingly support and solicit cervical cancer prevention services, they need to understand the need for the services and the benefits of their use. A cervical cancer prevention program's management team can facilitate the demand for and the utilization of services by developing effective I&E strategies—both community- and facility-based—and providing and conveying informational messages in culturally appropriate ways. Creating and using mass media to convey key messages can be advantageous; however, it is important to consider the extensive time and economic inputs that are required. Regardless of the type of I&E strategy used, consulting with clients and women in the community to help design the activities and content of educational materials is highly recommended.

In addition to developing I&E strategies that encourage women to solicit and attend screening services, it is important to devise strategies to help women navigate the screening and treatment process. Counseling is an essential part of any health service that enables a provider to respond to specific questions and alleviate any concerns that a client may have. Reducing a client's anxiety will likely enhance adherence to further management.

Information and education activities should target eligible women, their partners, and other family members. These individuals can be a tremendous support by helping to encourage eligible women to solicit screening and comply with follow-up instructions.

## **Further Reading**

Alliance for Cervical Cancer Prevention (ACCP). Fact Sheets. Seattle: ACCP; 2003[b]. Available at www.alliance-cxca.org/.

EngenderHealth. *Comprehensive Counseling for Reproductive Health: An Integrated Curriculum*. New York: EngenderHealth; 2003[c].

EngenderHealth. Counseling and Communicating with Men. New York: EngenderHealth; 2003[d]. Men's Reproduction Health Curriculum, section 2.

JHPIEGO. Talking with women about cervical cancer. In: *Cervical Cancer Prevention Guidelines for Low-Resource Settings*. Baltimore: JHPIEGO; 2003[a].

PATH. *Planning Appropriate Cervical Cancer Prevention Programs*. 2nd ed. Seattle: PATH; 2000.

## **Appendix 7.1. ACCP Education and Counseling Materials**

The materials listed (with the major themes they cover) are used in ACCP cervical cancer prevention projects. For electronic versions of ACCP materials, including I&E materials used in ACCP projects, please visit http://www.alliance-cxca.org/.

#### Information pamphlets

- What is cervical cancer?
- Who is at risk?
- How to prevent cervical cancer.
- What is the Pap smear?
- What is visual inspection with acetic acid (VIA)?
- What are treatment options for pre-cancerous conditions?
- Recommendations for follow-up after treatment.
- Explanation of national screening recommendations.
- Health facility location and hours for cervical cancer prevention services.

#### Posters and flyers (to hang in the health facility)

- How to prevent cervical cancer.
- The role of men in cervical cancer prevention.

#### Videos (to present in the waiting room)

- Cervical cancer is preventable and precursors can be detected through screening—death is an unnecessary consequence.
- Screening is a simple, painless procedure.
- Description of screening procedure.
- What to expect in case of a detected abnormality.
- Importance of undergoing screening even if a woman does not have symptoms.
- Role of men as advocates for women's health who support them to get screened.

#### Flip charts for use in counseling

- Overview of female reproductive organs.
- Risk factors associated with cervical cancer.
- Natural history/evolution of cervical cancer.
- Importance of informed consent.
- Explanation of cervical cancer screening procedures.
- Available treatment options for detected precancerous lesions.
- Potential adverse effects of precancer treatment options.
- Recommendations for follow-up after treatment.

#### Take-home instructions (after treatment with cryotherapy or LEEP/LLETZ)

- Self-care instructions, including sexual abstinence for 4 to 6 weeks following treatment.
- Potential side effects.
- When to seek medical attention.

## Appendix 7.2. Recommended Information and Education Materials for Cervical Cancer Prevention Services

Program managers can select recommended I&E materials listed here based on the screening test and treatment method used in their program.

#### Counseling flip charts for health care provider use with women prior to performing:

- Cytology
- HPV DNA test
- Visual test (VIA/VILI)
- Colposcopy
- Treatment (cryotherapy/LEEP)

#### Post-procedure instructions handouts for women:

- Cytology
- HPV DNA test
- Visual tests (VIA/VILI)
- Colposcopy
- Cryotherapy
- Biopsy/endocervical curettage
- LEEP

#### Job aids outlining procedures for health care providers (for hanging on wall):

- Infection prevention guidelines
- Pelvic exam instructions

## Training: Ensuring Performance to Standard

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## **Key Messages**

- The goal of training in a cervical cancer prevention program is to ensure that there are sufficient numbers of competent staff to attract women to utilize services, screen eligible women with an appropriate test, and treat eligible test-positive women.
- Competency-based training (CBT), which includes didactic, simulated, and hands-on (practical) training ensures that each trainee will be able to confidently provide an appropriately comprehensive service.
- Clinical training should be conducted just before launching services.
   This arrangement will avoid a possible loss of skills, which can happen if there is a long delay between training staff and providing services to the clients.
- To ensure performance to standard, the training system should include post-training follow-up and supervisory support to enhance transfer of learning at the workplace and enhance performance.
- To ensure sustainability, a training system should develop and support an in-country pool of trainers who are capable of training new providers and ensuring performance to standard.

#### Introduction

Training is an essential component of any cervical cancer prevention program. It prepares providers to deliver the program's essential services: attracting women to services, providing screening, and treating (or referring, as appropriate) those who test positive.

Countries wishing to implement new, or strengthen existing, cervical cancer prevention programs, whether using new or traditional methods and approaches, must build local capacity to do so. By necessity, these countries will probably choose in-service training of existing providers. It is the most efficient way to relatively quickly generate sufficient numbers of competent providers. Preservice education—that is, learning that takes place in medical, nursing, and midwifery schools—may eventually integrate training in skills necessary for cervical cancer prevention, but such considerations are beyond the scope of this manual.

Cervical cancer prevention training must not occur in isolation; rather, it should occur within the existing reproductive health training network. This training network is driven by reproductive health policies, dependent upon the structures and institutions that routinely produce health workers, and sustained by committed resources. Together, policymakers, health administrators, trainers, educators, clinical supervisors, physicians, nurses, and other health workers—ensure that providers have up-to-date, standardized skills and can deliver safe, high-quality reproductive health services. When functioning efficiently, the training network will develop in-country clinical trainers from the pool of expert providers.

Common challenges in training include: insufficient attention to hands-on (practical) training, often due to a low case load at the training center; undue emphasis on performing finite number of procedures, rather than on achieving competence; and inadequate post-training follow-up, periodic refreshers, or updates to ensure that cervical cancer prevention service providers are performing to standard. These common problems can be anticipated and avoided by following the guidance described below.

This chapter introduces the management team to basic concepts about training and ensuring performance to standard for cervical cancer prevention programs. It also provides a road map for facilitating the integration of cervical cancer prevention training into the existing reproductive health training network and describes strategies to avoid common problems. Although largely gained from VIA-based projects, the principles described here apply to any cervical cancer prevention method.

## The Role of the Management Team

The role of the management team in cervical cancer prevention training is to facilitate the development of the cervical cancer prevention training system, so that a continuous flow of new cervical cancer trainers and service providers are developed and deployed. This process includes assessing training needs regularly, conducting training courses, transfering learning activities, and routine supervision. It also must involve stakeholders and be consistent with local policies and objectives. In settings where new screening technologies, such as HPV DNA, VIA, or VILI are introduced, the management team must ensure coordination and communication among the individuals involved in planning, implementing, or participating in training.

## The trainer's responsibility on the management team

A training coordinator should be included as a member of the management team. This person's role is to facilitate learning—before, during, and after training—and to help each participant attain full competency. Therefore, the training coordinator should be involved in each aspect of training. A specific task group can be established to organize and oversee the training component of the program.

## **Planning for Training**

Planning for training in cervical cancer prevention programs should be based on the findings of the needs assessment (see Chapter 4) and should be consistent with national policies and service delivery guidelines. Prior to developing a training plan it is important to assess training needs, identify locally available training resources, and determine the need for external assistance. This activity can be conducted at the time of the initial needs assessment or as a separate, focused training needs assessment. The main focus areas of the training needs assessment are: assessment of institutions and facilities suitable for training; local availability of skilled providers; and the level of knowledge and skills that the participants bring to training, and what skills they need to develop further. During the planning process the management team should consider the following questions:

- How many providers should be trained based on screening coverage targets?
- What are the financial and other resource constraints?
- Who will be trained and for what component of the program?
- Who will be the trainers?
- What topics will be covered and what materials will be used to train the various service providers?
- Where will the training be conducted?
- When will the training be conducted and for how long?
- What are the arrangements to ensure transfer of learning?

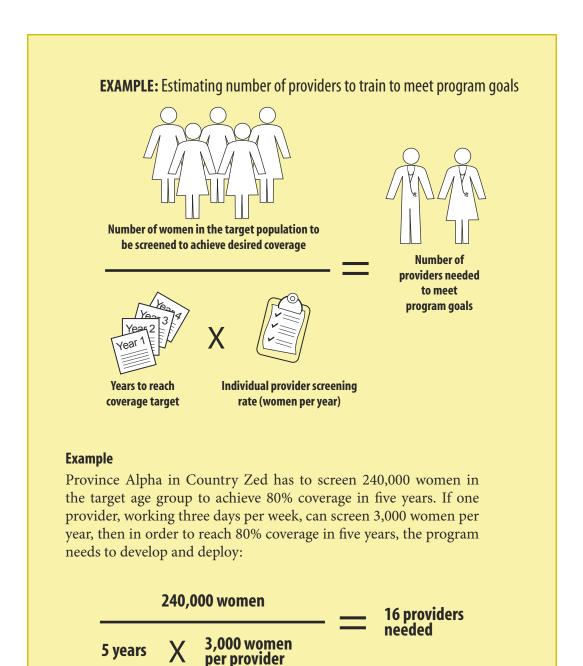
Another key consideration is timing; planning training programs requires considerable time and attention to detail. Ideally, planning should begin at least six months before the course. A typical timeline for planning activities is presented in Appendix 8.3. The management team should work with the training coordinator to plan activities such as assessing training needs and selecting participants.

#### **Budgeting for training**

The management team is responsible for determining the availability of financial and other resources that can be applied to training, and should ensure that all administrative arrangements for training courses (such as participant per diem) are addressed. For further detail, refer to Chapter 5.

## How many providers should be trained?

Various factors can affect the ability of a program to reach its targets. Screening coverage is an important target for cervical cancer prevention programs, because it has a profound impact on long-term disease reduction and cost-effectiveness. Although some factors, such as population growth rate, are beyond the control of the management team, the team should nevertheless consider locally defined coverage targets when planning for training. Factors that can be manipulated by the team include the number of providers and the rate of screening per increment of time. The box on page 154 gives an example of how to estimate the number of providers needed to meet program goals.



## Who will be trained?

The type and number of staff to be trained should be specified in the training plan. This decision will depend on the designated approaches to providing screening and treatment, the number and location of service delivery sites, and policies regarding what procedures can be performed by specific provider cadres. (See Table 8.1.) To meet defined program objectives, it is advisable that at least two providers from each service delivery site be trained so that they can support each other on the job.

**TABLE 8.1.** Suggested participants in program training courses

Program component	Cervical cancer prevention service provider
Community information and education	Community health workers, community health volunteers
Screening (cytology, HPV DNA, and visual methods)	Non-physicians* or physicians Cytology: cytotechnicians, pathologists
Diagnosis	Colposcopy: non-physicians or physicians Biopsy: non-physicians or physicians, pathologist
Treatment of precancer	Cryotherapy: non-physicians or physicians LEEP: physicians**
Monitoring and evaluation	Data managers, program manager, service providers, physicians. (If a computerized system is used, data managers should also be trained to use the appropriate software.)
Supervision	Health facility managers and local area (district) supervisors
Laboratory procedures (cytology, HPV DNA, histology)	Cytology: cytotechnicians, cytologists HPV DNA test training to be coordinated with the manufacturer. Histology: pathologists and technicians

<sup>\*</sup>Non-physicians are defined as nurses, nurse midwives, clinical assistants, and other allied cervical cancer prevention service providers who have been trained in these skills. Physicians can be general practitioners or gynecologists.

#### Who will be the trainer?

Based on the types or levels of staff to be trained, trainers should be selected with the appropriate background and experience. For example, clinical trainers should have two different skill sets. First, they must be skilled and experienced in performing the clinical procedures, including recognizing and managing the major and minor complications of the techniques to be taught. Second, they must be skilled and experienced in training. This expertise includes the ability to communicate effectively and to impart both theoretical and practical knowledge; to assess and adapt the training to suit the needs of individual cervical cancer prevention service providers; to use teaching aids such as films, slides, and simulation materials; and above all, to have a positive attitude about working with both clients and service providers.

<sup>\*\*</sup>In some developed countries LEEP is performed by specially trained nurses.

#### **Topics and training materials**

A complete training package for cervical cancer prevention should contain the following items:

- Reference manual that describes learning topics.
- Participant's handbook that describes the learning methods.
- Trainer's notebook that describes the teaching methods.
- Materials list, describing required classroom and clinic materials and supplies.
- Learning assessment instruments (e.g., learning guides).
- Performance assessment instruments (e.g., checklists).

The reference manual provides all of the essential information needed to conduct a course in a logical manner. It serves as the "text" for the participants and as the "reference" for the trainer; it obviates the need for multiple handouts. The participant's handbook serves as a road map to guide the service provider through each phase of the course. It contains a model course syllabus and schedule, as well as all supplemental printed materials. The trainer's notebook contains the participant's handbook materials and trainer-specific information, such as the course outline, answer keys, and competency-based knowledge and skill assessment instruments. ACCP members have developed cervical cancer prevention training tools that are tailored to various approaches (see Appendix 8.1).

Although the general principles of cervical cancer prevention must be included in all training, the level of information provided should be tailored to the level or type of provider being trained and the service component that is being addressed. In addition, the training objectives should address any specific knowledge gaps identified during the training needs assessment. For example, if information and education (I&E) activities for other health services are nonexistent, the training objectives for the health education and promotion component will need to include basic principles and approaches in addition to specific cervical cancer prevention issues. For a list of key topics to be included in training, based on the services to be provided and the level or type of staff, refer to Appendix 8.2.

## Developing and adapting a training package

Developing an effective training package is an essential component in implementing all prevention programs. Ideally, the training package should be educationally comprehensive, appropriate, up-to-date, focused, practical, accessible, distributable, culturally sensitive, easily understood by the intended audience, and feasible to implement. The management team can adapt existing training packages with the technical assistance of expert trainers.

#### Where will training be conducted?

Clinical training must take place at a location where facilities are available to provide both didactic and hands-on clinical training, with sufficient caseload to allow providers to observe and perform procedures under supervision. It is preferable that clinical training is conducted either where the service will eventually

be provided or at a facility that is similar to the cervical cancer prevention service providers' workplace. In this way, the service providers are more likely to transfer the skills from a learning environment to the service environment.

The effort expended in identifying the strengths and weaknesses of the site(s) and developing a good relationship with the staff will be paid back many times over when the participants have clinical experiences that allow them to become competent in the skills they need to complete the course successfully.

One of the most important considerations in selecting a training site is finding a good classroom that is near an appropriate clinical facility. The management team and trainer must weigh the advantages and disadvantages of selecting a training site close to where the majority of the participants work. Conducting a course in, or even near, the workplace can cause numerous interruptions and distractions. Conversely, the greater the distance the classroom and clinical sites are from the participants' work sites, the greater the costs of transportation and accommodation.

The management team, along with the trainer, should try to visit the clinical sites of some or all of the participants. This strategy has several advantages. The trainer can observe clinical skills, assess infection prevention practices, discuss client caseload, observe counseling procedures, and provide information to staff concerning the upcoming course. The management team and trainer are then in a better position to determine that the course objectives, content, and activities match the needs and capabilities of the participants. Furthermore, those attending the training will have established a relationship with the trainer and have a clearer understanding of what they will learn during the course.

The facility where the didactic sessions and model demonstration will be held should have space appropriate for the size of the participant group with sufficient tables, chairs, and desks. Rooms should be well-ventilated and have adequate lighting, as well as the necessary audiovisual equipment. Arrangements should also be made for accommodation and meals for the service providers and trainers.

## When will training be conducted?

Clinical training activities should be appropriately phased, with supervisors being trained with or prior to the providers in order to enhance transfer of learning and to ensure on-the-job support for skills development. If the program proposes to use nurses as providers with physicians as supervisors, then the physicians *must* be trained prior to the nurses, or else on-the-job support to the nurses will be tepid and inadequate.

#### **Timing**

It is best to conduct provider training "just in time," i.e., shortly before launching the program. There should not be a long delay between training staff and serving clients, lest the new skills be lost through lack of practice. Training for I&E staff can occur earlier, since they will need to promote screening services in the community before initiating clinical services.

#### **Training duration**

Ideally, clinical training should be of sufficient length to enable the average service provider to reach competency. In the real world, however, training length is constrained by resource availability and costs. The experience of ACCP members suggests that a minimum of five days and a maximum of ten days is required for competency-based training in VIA and cryotherapy. The duration of training for other cadres of health workers, such as data managers, should be determined by the training objectives, the participants' existing skills, and the training time available.

#### Administrative aspects of the training

The management team is responsible for all administrative arrangements related to planning and conducting training courses. Financial arrangements include determining how travel costs, per diem payments, and accommodation allowances will be paid to (or on behalf of) the participants. For an overview of the chronological steps involved in planning training courses, refer to Appendix 8.3.

#### **Build support of staff and coworkers**

To build support of staff and coworkers, the management team should conduct an orientation on cervical cancer prevention for all levels or types of staff at the participating health facilities before launching the services. This orientation will facilitate support for the services and enable inreach activities.

## **Developing a Training System for Cervical Cancer Prevention**

A training system for cervical cancer prevention programs comprises the constellation of institutions whose collective, coordinated efforts result in the development of new trainers and service providers. The goal of the system is to ensure a constant flow of these individuals, whose ranks may be diminished by planned retirement, redeployment, or other situations. In addition, the system also should provide opportunities for proficient service providers to develop increasingly higher levels of training skills.

It is desirable to use in-country trainers and training institutions as much as possible. Medical schools and specialized training centers can play a key role in providing and preparing training personnel. However, countries initiating a cervical cancer prevention program for the first time might need to collaborate with international organizations and universities that can provide technical assistance in conducting in-country training.

#### Process for becoming a clinical, advanced, and master trainer

A series of steps can be used to assist proficient service providers who are interested in becoming clinical trainers. The first step on the trainer pathway is for the proficient service provider to undertake a specialized course in clinical training

skills, thereby earning the status of candidate clinical trainer. Under the guidance of a master trainer, the next steps for the candidate clinical trainer are:

- Co-train a course for new service providers, thereby earning the status of qualified clinical trainer.
- Undertake a specialized course in advanced clinical training skills.
- Co-train a course for new clinical trainers, thereby earning the title of master trainer.

For more details, an example of the trainer pathway can be found in Appendix 8.4.

#### Approaches to training

Training is obtaining the knowledge, attitudes, and skills needed to carry out specific activities or tasks. It also presumes that the knowledge and skills will be immediately applied. Training is a broad, complex field, and full treatment of its complexities is beyond the scope of this chapter; however, there are some concepts that the cervical cancer prevention management team should know.

#### Goal of cervical cancer prevention training

The goal of cervical cancer prevention training is to develop core groups of providers who are competent in the skills needed to attract women to services, screen eligible women with an appropriate test, and treat eligible test-positive women as indicated. In some settings, one cadre of providers will perform all three of these tasks; in others, there may be a division of labor among a variety of different cadres. In either case, training is essential. Effective cervical cancer prevention training is designed and conducted so that learning is participatory, relevant, and practical (Sullivan et al. 1998).

#### Competency-based training (CBT)

CBT is an approach that has all of the key features of effective clinical training. CBT is learning by doing; it focuses on the specific knowledge, attitudes, and skills needed to carry out a procedure or activity (Sullivan et al. 1998). Emphasis is put on the participant's performance, not on his or her ability to retain information.

What I hear, I forget;
What I see, I remember;
What I do, I understand.

Confucius

Competency in the new skill is assessed objectively by evaluating overall performance according to established standards.

#### **Skill standardization**

To facilitate CBT, the sequence of essential steps in the procedure must be standardized based on the safest and most essential method to perform the procedure. Once a skill is standardized, training instruments such as learning guides and checklists are developed. Learning guides describe in detail the sequence of steps in the procedure, and checklists enable the assessment of trainee performance.

#### Didactic, simulated, and behavior modeling techniques

CBT requires the trainer to facilitate and encourage learning, rather than serve in the more traditional role of instructor or lecturer. Nevertheless, didactic techniques like lectures and oral presentations can be used to convey the key principles, supporting evidence, and the rationale of the various clinical methods and approaches involved in cervical cancer prevention and treatment. Lectures can be enlivened by participatory activities such as questioning, group discussions, and audiovisual aids. Yet didactic lectures, no matter how lively, cannot prepare providers to do their jobs.

The use of simulated training techniques contributes to better clinical training. Simulated training involves the use of anatomic models and other learning tools, such as cervix image (see the two boxes opposite). The effective use of models and images facilitates learning, shortens training time, and minimizes risks to clients.

#### **Demonstration and practice**

Trainers should demonstrate required skills and client interactions several times using anatomic models and appropriate audiovisual aids. Trainees should use learning guides to follow along and to practice the steps. Classroom practice with anatomic models can be enhanced by the use of checklists, which summarize the essential steps of the newly acquired clinical skill.

The duration of the demonstration and practice sessions, including the number of procedures participants need to observe, will vary depending on their backgrounds and on the skills being taught. Participants should have their first contact with clients only after competency and some degree of proficiency have been demonstrated with models.

It must be noted that some participants are able to acquire new knowledge or a new skill immediately, whereas others require additional practicum time after the training sessions or alternative learning methods before they can demonstrate competence. To extend practical training after the initial training workshop, one of the methods that can be used is to assign trainees as "apprentices" with an experienced provider at a facility close to the trainee's workplace. This assignment can be arranged as a rotation on a weekly or monthly basis. The most important element is to ensure that each trainee gets adequate practical experience so she or he can gain confidence and can conduct the procedures competently.

#### **Learning Aids for Visual-Based Screening Skills**

In addition to practice using anatomic models, training in visual-based screening test skills is enhanced by the use of cervix images. Just as training slides exist for cytology programs, all ACCP members have developed cervix image tools in their cervical cancer prevention training packages. These images can be used as learning or performance assessment tools, both during training and afterward. Examples include JHPIEGO's flash card set, in which each cervix image is accompanied by descriptive information (shown here).



Flash cards

#### **ZOË© Pelvic Model**

The ZOË® Gynaecologic Simulator is a full-sized model of an adult female abdomen and pelvis. It is a versatile training tool developed to assist health professionals to teach the processes and skills needed to perform many gynecological procedures. The ZOË® model is ideal for demonstrating and practicing:

- Vaginal speculum examination
- Technique of doing screening tests (taking a Pap smear, HPV DNA tests, and visual tests)
- Visual recognition of normal cervices and cervical abnormalities
- Technique of placing the cryotherapy probe
- The use of female condoms

It can also be used to demonstrate other gynecological procedures, such as uterine sounding, treatment of incomplete abortions using manual vac-



ZOË© Gynaecologic Simulator

uum aspiration, and family planning procedures (intrauterine device insertion and removal, sizing and fitting diaphragm, and female sterilization).

#### Skill assessment

Competency-based skill assessment can measure knowledge, skills, and other observable behaviors relative to an established performance standard. The same checklists that were used during classroom practice should be used to objectively evaluate performance, so that trainers can ensure that all service providers have their skills measured by the same standard. Checklists can also be used to follow up with providers after training, to determine the degree to which new knowledge and skills are applied in the workplace—also known as "transfer of learning."

#### **Documentation of competence**

Training institutions may provide statements of qualification, which confirm that the individual has met the requirements of the course in terms of knowledge, skills, and practice. Certification, on the other hand, is bestowed by an authorized entity, such as the Ministry of Health, a medical school, or a nursing school.

#### Whole-site training

Whole-site training is an approach to training that emphasizes the use of the service site as much as possible. It involves all levels of staff at the site and includes ongoing supervision (Bradley et al. 1998). Whole-site training attempts to meet the learning needs of all staff. It emphasizes the development and training of teams of providers, so that services will continue when individuals are on leave (or are transferred to another site). There are two key benefits of this approach. First, since skills are learned in the cervical cancer prevention service providers' own workplace, new skills and services are more readily implemented. Second, orientation programs can be simultaneously provided to all staff to enhance promotion of and support for the cervical cancer prevention program.

# **Transfer of Learning**

# The principle

Transfer of learning is the intensive phase of performance assessment that occurs immediately after training and ensures that new skills are applied in the workplace after training ends. This stage is the link between training and routine supervision. It is a process of interrelated tasks, performed by on-site supervisors, trainers, service providers, training stakeholders—before, during, and after training—to maximize the application of new knowledge and



"Hands-on" clinical practice helps health care workers develop skills and confidence.

skills. Properly implemented, transfer of learning can help to ensure that cervical cancer prevention service providers are performing to expected standards.

#### **Transfer of learning techniques**

Transfer of learning techniques assesses providers' ability to perform the procedure, determine the test result, and use clinical judgment to decide whether to offer treatment or referral. The process is a team effort, involving training participants (cervical cancer prevention service providers), trainers, clinical supervisors (where they exist), on-site supervisors, coworkers, and others. The involvement of all team members can help to reemphasize transfer of new knowledge and skills on the job.

Depending on local resources and trainer availability, the frequency and number of transfer of learning visits may vary. In general, visits should be conducted once or twice per month during the three-to-six-month period immediately after training, until providers are reassessed as competent in two subsequent visits.

Transfer of learning techniques are used by the trainer—ideally, the same individual who conducted the initial course—who observes the provider performing procedures (screening, treatment, counseling, etc.) in the routine clinic setting. Training checklists are the primary assessment tools for observations of provider performance. In settings where visual-based methods are used, clinical observation can be supplemented using cervix images such as flashcards to assess provider performance to standard.

If problems are identified, the trainer collaborates with the provider to design a strategy for performance improvement. Finally, the trainer prepares a summary report, describing findings and specific recommendations, for the management team. It is important that this report be shared with individual providers.

# Role of the management team in transfer of learning

The management team is responsible for facilitating transfer of learning visits and for ensuring that they take place. In the event that performance problems are identified, the management team can work with the on-site supervisor or local clinical supervisor to arrange strategies for corrective action.

# **Ensuring Performance to Standard**

## The principle

Ensuring performance to standard is the ongoing phase of assessing provider performance that occurs after the transfer of learning phase ends. The principles are the same as in transfer of learning; they take into account both individual performance factors and the programmatic impact. In contrast to the transfer of learning phase, the ensuring performance to standard phase can be implemented by health administrators or local area supervisors.

#### Performance standards and indicators

National policies define individual performance standards. Performance indicators are used to assess whether individual performance meets these standards. These indicators should be developed within each country setting. Table 8.2 describes a few sample indicators for provider performance.

**TABLE 8.2.** Sample performance indicators for individual performance

Program activities	Individual performance indicator	How to calculate	Options for corrective action
Counseling	Proportion of counseling sessions performed to standard	Number of counseling sessions performed to standard/number of coun- seling sessions performed	Refresher training in counseling for cervical cancer prevention
Screening	Cytology: proportion of adequate smears	Number of adequate smears/total number of women screened.	Refresher training in obtaining a smear sample
	Visual-methods example: rate of agree- ment between pro- vider's assessment and trainer or clinical supervisor's assessment	Number of concordant assessments/number of provider and trainer or clinical supervisor assess- ments	Provider self-assessment using cervix image flash- cards or CD-ROM and refresher training
Treatment	Treatment rate to standard, by provider	Number of clients receiving treatment/number of test-positive clients eligible for treatment per provider	Analyze root cause for low treatment rate, select interventions, and monitor performance again

#### Role of the management team in ensuring performance to standard

The role of the management team is to facilitate linkages between trainers and onsite supervisors, so that mechanisms for ensuring performance to standard are integrated into routine activities at the site and thereby sustained.

For more detailed information regarding overall programmatic performance, including core process indicators, refer to Chapter 9.

#### **Conclusion**

Training is a broad and complex subject, but there are basic principles that the program management team should follow. To plan and develop the cervical cancer training system, the management team must work closely with experienced cervical cancer prevention trainers. At the beginning of a new country program, these may be external expert trainers; but eventually, local training experts should be developed and involved in maintaining the training system.

The cervical cancer prevention training system should be flexible enough to integrate new screening and treatment technologies as they emerge. When CBT is integrated with didactic and behavior-modeling techniques, the result is an extremely effective method for conducting cervical cancer prevention training. And, when supervised practice using anatomic models and other learning aids is also integrated, both training time and training costs can be reduced significantly. If training is provided through incorporation into a preservice program, then certification may be included in the final degree granted.

Transfer of learning helps to ensure that new knowledge and skills are applied in the workplace. Ensuring performance of providers is essential to the effectiveness of cervical cancer prevention programs. Individual performance should be monitored on an ongoing basis, and individual performance indicators, as defined by national and local policies, should be used to do so. Strong linkages between training and on-site supervision can help to address and resolve performance gaps.

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# **Appendix 8.1. List of Training Tools**

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# Appendix 8.2. Cervical Cancer Prevention: Key Training Topics and Rationale

Key training topics	Content elements	Rationale
Magnitude of the problem and the role of screening programs.	<ul> <li>Relevant data on incidence, prevalence, and mortality from cervical cancer for the country and the region.</li> <li>Barriers to prevention.</li> <li>Why prevention is desirable.</li> <li>Key elements of a screening program.</li> </ul>	Provides a public health context for cervical cancer and emphasizes what can be done to reduce the burden of the disease.  Explains rationale for selecting target age group, frequency of screening, and treatment of precancer. Prepares health care workers at all levels to educate the public about the nature of the disease and how prevention works. Also de-stigmatizes cervical cancer by emphasizing prevention.
Natural history of cervical cancer.	<ul> <li>Role of HPV infection in precancer.</li> <li>Precancer.</li> <li>Progression of precancer to cancer.</li> <li>Cervical cancer.</li> </ul>	Provides background to explain target age group, frequency of screening, and treatment of precancer. Prepares health care workers at all levels to educate the public about the nature of the disease and how prevention works. Also de-stigmatizes cervical cancer by emphasizing prevention.
Applied anatomy and physiology of the female genital tract.	<ul> <li>Transformation zone, squamo-columnar junction, and physiological changes.</li> <li>Appearance of normal cervix, normal variants, benign conditions of the cervix, and changes with age.</li> <li>Hormonal influences, e.g., pregnancy, and inflammatory changes of the cervix.</li> <li>Clinical features of reproductive tract infections and STIs.</li> </ul>	Provides necessary background in anatomy and physiology to perform screening, diagnosis, and treatment procedures.
Client assessment.	<ul> <li>History taking.</li> <li>Clinical examination including pelvic examination.</li> </ul>	Refreshes basic clinical skills, particularly because pelvic examination is not performed routinely in many family planning and STI clinics.
Counseling.	<ul> <li>Client-provider interaction and the consequences of poor communication.</li> <li>Clients' rights.</li> <li>Confidentiality, privacy.</li> <li>Informed decision-making and informed consent.</li> <li>Counseling skills.</li> <li>Counseling messages prior to screening, diagnosis and treatment, and post-treatment procedure.</li> </ul>	Emphasizes the role of counseling to address key issues of ensuring informed and voluntary participation in the screening program and compliance with follow-up instructions.

Key training topics	Content elements	Rationale
Screening tests (cytology, HPV DNA, visual methods).	<ul> <li>For each test in which training is provided:</li> <li>Principles.</li> <li>Description.</li> <li>Test characteristics.</li> <li>Implications.</li> <li>Strengths and limitations.</li> <li>Steps involved.</li> <li>Define what constitutes a positive test.</li> <li>Nature of the lesion needing treatment.</li> <li>Using standardized terminology.</li> </ul>	Develops judgment necessary for effective visual screening, establishes clear criteria for identifying positive lesions, and emphasizes importance of standardized categorization (test results) for communicating within and between prevention programs.
Management of cervical precancer (diagnosis and/or treatment).	<ul> <li>Colposcopy and biopsy.</li> <li>Approaches to treatment.</li> <li>Treatment options available in the program.</li> <li>Treatment steps.</li> <li>Required equipment.</li> <li>Program considerations behind treatment.</li> <li>Selecting clients suitable for treatment and management of women not suitable for a particular treatment method.</li> <li>Benefits and limitations of treatment.</li> <li>Associated side effects.</li> <li>Possible complications.</li> <li>Recognizing and managing complications.</li> <li>When, whom, and where to refer.</li> <li>Treatment failure.</li> <li>Continuity of care.</li> </ul>	Familiarizes trainees with treatment options and develops clinical skills; emphasizes how to prevent, recognize, and manage complications; and clarifies when they are able to treat a women and when she must be referred elsewhere.

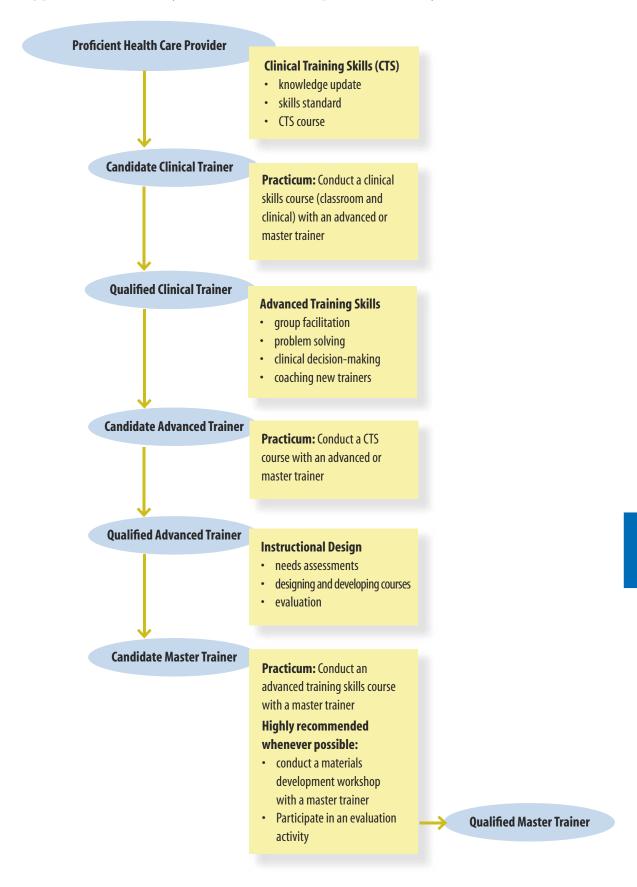
Key training topics	Content elements	Rationale
Infection prevention.	<ul> <li>Why it is important.</li> <li>Elements of infection prevention.</li> <li>Decontamination, cleaning, high-level disinfection, and sterilization.</li> <li>Disposal of waste.</li> </ul>	Emphasizes importance of protecting both clients and health workers from communicable diseases through safe work practices and environments.
Documenting and reporting clinical findings and test results.	<ul> <li>Key findings that should be documented.</li> <li>Recording findings clearly and methodically.</li> <li>Integrating documentation into clinical practice.</li> </ul>	Emphasizes importance of consistent documentation and record keeping in preventing loss to follow-up and health-related consequences associated with missed diagnoses or treatment.
Follow-up of women who have been treated.	<ul> <li>Rationale for follow-up.</li> <li>When to follow up.</li> <li>Duration of follow-up.</li> <li>What should be done at the follow-up visit.</li> </ul>	Facilitates continuity of care.
Overview of the management of cervical cancer.	<ul> <li>Clinical features, staging, and investigations.</li> <li>Treatment of cervical cancer.</li> <li>Palliative care—principles of supportive care and managing the symptoms of advanced cancer.</li> </ul>	Provides background information to enable trainees to counsel, refer, and follow up women with cervical cancer, whom they will inevitably encounter in a prevention program.
Data management.	<ul> <li>What a health information system (HIS) is.</li> <li>Description of HIS used in the program.</li> <li>The importance of HIS for cervical cancer prevention program.</li> <li>Use of process and outcome indicators.</li> </ul>	Emphasizes the role of HIS and how it enables taking corrective action and improving program performance.

# Appendix 8.3. Checklist for Preparing a Workshop/Training Course

Six months prior to course	Three months prior to course
<ul> <li>□ Confirm training site(s).</li> <li>□ Select accommodation (if necessary).</li> <li>□ Select and confirm additional trainers, consultants, or content experts (if necessary).</li> </ul>	<ul> <li>□ Select and notify participants.</li> <li>□ Initiate administrative arrangements.</li> <li>□ Confirm accommodation.</li> <li>□ Reconfirm availability of trainers, consultants, or content experts.</li> <li>□ Order training materials, supplies, and equipment.</li> <li>□ Confirm arrangements to receive participants at clinical training facility.</li> </ul>
One month prior to course	One week prior to course
<ul> <li>□ Review course syllabus, schedule, and outline and adapt if necessary (send copies to participants and trainers).</li> <li>□ Review course content and prepare for each session to be delivered by clinical trainer (e.g., prepare trainer's notes if used).</li> <li>□ Prepare audiovisuals (transparencies, slides, flip charts, etc.).</li> <li>□ Visit classroom site and confirm arrangements.</li> <li>□ Visit clinical training site(s) and confirm arrangements.</li> <li>□ Confirm receipt of educational materials, supplies, and equipment.</li> <li>□ Finalize administrative arrangements (e.g., local transportation to and from training site).</li> <li>□ Reconfirm housing arrangements.</li> </ul>	<ul> <li>□ Review final list of participants for information on experience and clinical responsibilities.</li> <li>□ Assemble educational materials.</li> <li>□ Prepare certificates of attendance.</li> <li>□ Reconfirm availability of clients at clinical training site.</li> </ul>
One to two days prior to course	
<ul> <li>□ Prepare classroom facility.</li> <li>□ Prepare and check audiovisual and other traini</li> <li>□ Arrange anatomic models and all needed instruction</li> <li>□ Meet with trainer, outside consultants, or contemps of the consultants or contemps.</li> </ul>	uments.

Source: Sullivan et al. 1998.

# **Appendix 8.4. Faculty and Trainer Development Pathway**



Source: Adapted from Blouse et al. 1998.

#### q

# **Improving Program Performance**

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# **Key Messages**

- Continuous proactive monitoring and appropriate corrective actions, using the quality improvement tools and a health information system (HIS), will enhance the effectiveness of a cervical cancer prevention program.
- There is a need to focus on processes and systems, recognizing that poor-quality of program performance is often due to weak systems and processes rather than individuals.
- An effective HIS, based on valid and measurable indicators, is an essential tool for tracking clients and monitoring program performance.
- Health information systems may be either facility-level or centralized.
  In both systems the keys to their effectiveness are routine collection
  of essential data and generation of regular monitoring reports and
  tracking lists for supervisors and the management team.

#### Introduction

Program performance refers both to quality of care and the attainment of quantitative outputs toward defined program goals. Monitoring and evaluation are essential to ensure that all aspects of care function effectively and efficiently through the efforts of frontline workers. It should be a continuous process that derives from the interaction among information systems, supervisory quality assurance efforts that define and ensure adherence to standards, and self-assessments by health workers through the participatory quality improvement process.

The management team is responsible for making certain that the program is providing quality services that are appropriate, affordable, accessible, and cost-effective. To fulfill this task, the management team should actively participate in the ongoing monitoring and evaluation process and ensure that systems are established and functioning efficiently. Specific tasks include:

- Assessing program progress toward goals and targets, using clearly defined and measurable indicators.
- Ensuring that information is collected, summarized, and reported through an established and properly functioning HIS and other qualitative quality improvement tools.
- Using the data to implement corrective actions in a process of continuous performance improvement.
- Involving staff in the quality improvement process.

#### **Program Improvement Process**

#### Monitoring and evaluation framework

Monitoring and evaluation helps the management team to:

- Determine the extent to which the program is meeting the stated goals, objectives, and targets and make corrections accordingly.
- Make informed decisions regarding program management and service delivery.
- Ensure the most effective and efficient use of resources.
- Evaluate the extent to which the program is having the desired impact.

All these activities aim at improving program performance.

The monitoring and evaluation process is based on a clear logical pathway (see Table 9.1). It starts with program "inputs" (personnel, training, equipment, funds, etc.) that are made in order to attain "outputs" such as available, accessible, and reliable client-centered screening, treatment, and other supportive care services. Ensuring availability of competent personnel to provide good-quality screening and treatment services to a large proportion of women in the target age group can achieve program "outcomes" such as high screening coverage and a high rate of test-positive women who have received treatment for precancer, which in turn can reduce the burden of the disease (impact).

**TABLE 9.1.** Monitoring and evaluation framework

	ORING valuation		ATION s evaluation
Inputs	Outputs	Outcomes	Impact
<ul> <li>Staff</li> <li>Money</li> <li>Supervision</li> <li>Facilities</li> <li>Equipment</li> <li>Supplies</li> <li>Training</li> <li>Program plan</li> </ul>	<ul> <li>Available screening and treatment services</li> <li>Quality services</li> <li>Competent staff</li> <li>Knowledge of cervical cancer prevention</li> </ul>	<ul> <li>Screening coverage</li> <li>Treatment rate for women with precancer lesions</li> <li>Behavior change</li> <li>Increase in social support</li> </ul>	<ul> <li>Incidence of cervical cancer</li> <li>Mortality from cervical cancer</li> <li>Economic impact</li> <li>Social impact</li> </ul>

Source: Adapted from UNAIDS and the World Bank 2002.

Most of the outcomes can be measured using indicators corresponding to the main goals of a cervical cancer prevention program: to reduce disease by attracting women to utilize services, screening eligible women with an appropriate test, and ensuring appropriate management of test-positive women. Capacity (outputs) reflected by quality indicators, has a significant impact on the utilization of services, which in turn will affect the program performance. For example, if client satisfaction is low or recruitment strategies are inappropriate or ineffective, coverage

and participation will be low. Finally, as indicated by the above framework, a prevention program can achieve its ultimate goal (impact)—reduction of cervical cancer incidence and mortality—when the outputs and outcomes are achieved.

#### Improving quality of services

Monitoring should focus on quality of care since improving the quality of services contributes to efficiency and cost savings, promotes job satisfaction among employees, and attracts clients to screening and treatment services. Factors such as client satisfaction or preferences are difficult to measure; however, there are qualitative tools and approaches that can be used to assess client satisfaction, analyze problems identified, and develop solutions to improve quality of services at the facility level. These quality improvement activities should become a part of routine service delivery and carried out every few months, with remedial actions managed on a daily basis. Improving quality is the responsibility of all staff at a site; therefore, it is important that a broad range of staff at all levels participate in quality improvement activities.

#### **Client exit interviews**

Obtaining constructive feedback from clients is integral to program effectiveness because it offers providers an opportunity to strengthen their interactions with women seeking care. Clients' perceptions of the services can be gathered in "exit interviews" using semi-structured, open-ended questionnaires. Such interviews are done by talking with clients when they leave a facility, inquiring about their experience at the health facility. Inquiries include how they felt they were treated by their provider, and whether or how the services they received might influence their intentions to seek treatment or follow-up care, if needed, or to recommend services to other women (WHO and ACCP forthcoming).

#### COPE®\*

COPE (client-oriented, provider-efficient services) is a process and set of tools for health care staff to continuously assess and improve the quality of their services. It is a built on a framework of clients' rights and staffs' needs. COPE consists of four tools: self-assessment guides (one for each of the clients' rights and staffs' needs), a client interview guide, client-flow analysis, and an action plan. The self-assessment guides encourage staff to review the way they perform their daily tasks and serve as a catalyst for analyzing the problems they identify. The guides contain key questions based on international clinical and service standards, and the safety guide includes a medical record review. The tools also highlight client-provider interactions and other areas of concern to clients. (See the box on next page.)

Facility staff should conduct COPE exercises periodically, focusing on systems and process. Findings from COPE exercises are then discussed by the whole group and a COPE action plan is developed, listing each of the problems identified, the root causes of each problem, the actions recommended to solve each problem, the staff members responsible for implementing the recommended actions, and the completion date for each action. Client exit interviews are an integral part of COPE. For further details on COPE exercises and tools refer to the Further Reading section of this chapter.

<sup>\*</sup> COPE is a registered trademark of the U.S. Patent Office.

#### **Examples of COPE Tools**

#### Self-assessment guides including record review checklist

The COPE self-assessment guides are a set of trigger questions that help staff think about the way services are provided and whether adequate supervision, training, and equipment are available at their site. One component of the self-assessment concerns the client's right to safety. Ensuring that patient health records are up-to-date and accurate contributes to the client's safety. Staff uses this record review checklist to determine whether essential information is being recorded accurately and completely in patient records and whether patients are receiving care according to standards.

#### **Client interview guide**

Staff use the interview guide to learn clients' views and opinions of the services provided at their site. The interviewers encourage selected clients to discuss their perception of services, what was good and bad about the visit that day, and to suggest how the services could be improved.

#### **Client-flow analysis**

This is a method for staff to track clients from the time they enter a facility for services until the time they leave, to identify periods of unnecessary waiting for clients, and to increase the efficiency of using providers' time.

#### **COPE** action plan

The action plan is a written plan that staff develop to help resolve the problems they identify during a COPE exercise. When COPE participants have completed the self-assessments and record reviews, client interviews, and client-flow analysis (if performed), they convene at the action plan meeting to discuss, consolidate, and prioritize the problems and recommendations. The COPE action plan for the facility lists:

- Each problem identified.
- Root causes of each problem.
- Actions recommended to solve each problem.
- Staff members responsible for implementing the recommended actions.
- Completion date for each action.

#### **Facilitative supervision and mentoring**

Facility, clinical, and area supervisors play a key part in monitoring and evaluation and in ensuring quality services. "Facilitative supervision" is an approach that emphasizes the supervisor's role in helping bring about quality improvement among a team of staff. It emphasizes mentoring, joint problem solving, and two-way communication between a supervisor and those being supervised. To facilitate change and improvement and to encourage staff to solve problems, supervisors must have the solid technical knowledge and skills needed to perform tasks, know how to access additional support as needed, and have time to meet with the staff they supervise.

Sufficient time should be allocated for each supervisory visit to the facility, which should be an ongoing activity (see Chapter 8). Observing all aspects of service provision—client registration, counseling, screening, treatment, infection prevention and documentation, and reviewing client records and facility registers—will enable the supervisor to determine if client management is according to standard and that documentation is complete. Supervisors need to ascertain that functioning equipment and supplies are and have been available at the facility. They should also review site-level data with facility staff, looking at recruitment, coverage, screen abnormality rates, turnaround times (where laboratories are used), adequacy rates (cytology), and treatment rates. Above all, they should use this opportunity to mentor and update providers and work with them to jointly solve any issues.

#### Improving program outcomes

To create the appropriate system for measuring program functioning and outcomes, managers need to define and focus on critical indicators of program performance. Table 9.2 presents indicators for each program goal in terms of program elements to monitor, the indications denoting aspects needing improvement along with suggested corrective action. A key concept to remember is that data *quality* is more important than *quantity*. An HIS enables collecting and processing the essential data to monitor the program outcomes. Detailed information on HIS is provided in the next sections.

TABLE 9.2. Program indicators and associated corrective actions

Program goal	Program elements	Indications denoting need for improvement (Indicators are in bold)	Suggested corrective actions
Attract women to services	Client participation*	Decrease in <b>the number of newly screened women per month</b> (in relation to the expected monthly target)	<ul><li>Step up active recruitment of women.</li><li>Revise recruitment methods.</li></ul>
	Appropriate target age group*	Excessive proportion of clients out of the target age group for screening (>5%)	<ul><li>Train staff on need to screen target age group.</li><li>Revise recruitment strategy.</li></ul>
	Inappropriate rescreening  (This element refers to the number of women who were repeatedly screened before the specified period, i.e., not in accordance with the policy on frequency of screening.)	Excessive <b>rate of inappropriate</b> rescreening (>10%)	<ul> <li>Emphasize with community and providers the need and rationale for focusing on unscreened women and avoiding inappropriate rescreening.</li> </ul>

\*While all elements are important, programs with limited resources should place special emphasis on these elements.

Program goal	Program elements	Indications denoting need for improvement (Indicators are in bold)	Suggested corrective actions
Screen women with a good test	Test quality (visual inspection)*	<b>Test-positive rate for VIA or VILI</b> out of expected range (5%–25%)**	Conduct refresher training in visual inspection.
	Test quality (cytology)*	Inadequate Pap smear rate out of the expected range (>10%) Rate of high-grade squamous intraepithelial lesions (HSIL) detected by cytology out of expected range (1%–5%)**	<ul> <li>Conduct refresher training for smear takers or laboratory screeners.</li> </ul>
	Test quality (HPV DNA testing)*	<b>Test-positive rate for HPV</b> out of expected range (5%–25%)**	<ul><li>Conduct refresher training for sample takers.</li><li>Check sample storage and transportation.</li></ul>
	Laboratory processing	Length of time it takes for test results to return from lab (> 4 weeks)	<ul> <li>Review laboratory capacity.</li> <li>Improve laboratory working process.</li> <li>Improve transportation system to and from the laboratory.</li> </ul>

\*While all elements are important, programs with limited resources should place special emphasis on these elements.

<sup>\*\*</sup>This is the likely range in an unscreened population. Rates will be lower for a previously screened population. This rate is also affected by the prevalence of STI/HIV in that population.

Program goal	Program elements	Indications denoting need for improvement (Indicators are in bold)	Suggested corrective actions
Ensure appropriate treatment and management of test-nositive women	Diagnostic	Marked change (either increase or decrease) in the rate of high-grade lesions at colposcopy/biopsy	<ul> <li>Conduct refresher training for sample takers.</li> <li>Conduct refresher training for colposcopists.</li> <li>Conduct refresher training in histology.</li> </ul>
	Treatment of test-positive women or women with high-grade lesions*	Less than 90%-100% rate of treatment within 6 months of the women who screened positive (or with high-grade lesions)	<ul> <li>Improve counseling, education, and information.</li> <li>Ensure tracking system and referral services are functioning.</li> <li>Investigate barriers to patients accessing treatment (cost, transport, other).</li> </ul>
	Management of cancer	Low <b>rate of women who show up for treatment</b> after being referred to a cancer facility (<80%)	<ul> <li>Improve counseling and information.</li> <li>Investigate barriers to patients accessing treatment (cost, transport, other).</li> <li>Ensure functional referral services.</li> </ul>
	Post-treatment assessment for precancerous lesions	Low proportion of women "cured" at one year post-treatment (<85%)	<ul> <li>Check adequacy of diagnosis and treatment performed.</li> <li>Retrain staff in treatment.</li> </ul>
		High rate of major post-treatment complications (>1%)	<ul> <li>Retrain staff in treatment and disease management.</li> <li>Check if selection criteria for treatment are appropriate.</li> </ul>

\*While all elements are important, programs with limited resources should place special emphasis on these elements.

# **Taking corrective actions**

Monitoring program performance should be a continuous process, involving the collection, analysis, and review of both quantitative and qualitative indicators for the program. Collecting numbers or developing the perfect indicators is not useful unless data are reviewed, interpreted, and then used to make decisions on how to improve the program. The information collected using HIS and qualitative tools must be used by supervisors, stakeholders, and all staff providing services to identify the cause of the problem and appropriate solutions. Corrective actions required to improve program performance should then be identified and implemented in a timely manner. Continual monitoring should ensure that corrective actions are indeed improving the program's performance.

# **Establishing a Health Information System**

#### Objectives of the health information system

The purpose of the HIS is to periodically generate data on the quantitative indicators for each program element to monitor progress and identify those indicators that need improvement. An HIS *also* can be used to monitor individual client management. For example, appropriate treatment and management of test-positive women is a critical factor in program performance. The HIS can generate data on the status of *each* woman involved in the program and categorize clients as follows:

- Group A: Women with negative screening test.
- Group B: Women with a positive screening test who have undergone diagnosis and/or treatment (completed clinical management).
- Group C: Women with a positive test who were not treated, or were treated but lost to post-treatment follow-up (incomplete clinical management).

Such data enable monitoring both the treatment and the follow-up rate for women with precancerous lesions, as well as identification and tracking of individual women needing further management. The ultimate purpose of generating this data is to monitor and, if indicated, take actions to minimize the number of women in Group C.

#### **Factors to consider**

Measurement of progress in program indicators requires an HIS that generates quality data in a timely way. In many countries, however, such systems are absent or function poorly. Critical information required for patient management and for effective planning, management, monitoring, and evaluation of programs is frequently unavailable. Some needs have to be addressed when establishing an information system:

Need for standardization. Program monitoring is greatly facilitated when
using standardized definitions, algorithms for clinical management, and
classification systems (for example, terminologies used in cytology).

- Need to train service providers on HISs. Frontline health care workers should understand the HIS and why they must complete clinical forms and adhere to procedures for data collection and reporting.
- *Need for appropriate links*. Information systems have to be linked across the primary, secondary, and tertiary levels of the health care system, and between the public and private sectors. This linkage enables staff to track clients effectively within the health care system and to assess the overall program impact.

## **Basic principles**

Keeping the above factors in mind, certain basic principles of the HIS should be followed in order for systems to be affordable and user-friendly and for data to be valid, collectable, and useful.

- Keep it simple. Collect only essential data that will be used for monitoring and management of the program.
- Ensure that accurate and appropriate data are collected. This principle requires training health workers in the rationale behind data collection, the process of collecting screening data, and the basics of information system design and management, even for information systems relying on registers (paper-based).



Accurately recording client information is the basis of an effective HIS.

- Appoint a responsible person at each reporting level to oversee the data collection system, organize training in data collection, ensure the flow of the information, generate reports, and liaise with the cervical cancer screening program management.
- Link outputs to program improvement. Action must be taken where problems are identified. Feedback can be given during routine supervisory visits.
- Integrate the cervical cancer prevention HIS into routine services to ensure sustainability.
- Protect clients' right to confidentiality.

#### Confidentiality

Confidentiality is a fundamental right of clients. Clients' names and medical information should be kept private and shared only with medical staff as necessary for client management. In addition, paper files should be stored properly and only accessible to specific staff members. In computer systems, the HIS database should be locked by a password to prevent access by unauthorized persons.

#### Client identification

Programs should use an individual client/patient identification (ID) card (see Appendix 9.1). At the time of the first screening visit, each client should be given a card and assigned an ID number or code (e.g., facility ID and patient clinic/hospital number). This number can be allocated at the local level, at the first screening visit, and it should then appear on every form associated with the cervical cancer prevention program to facilitate tracking and follow-up. In addition to making it easier to trace the client record, this card will allow the provider to know the status of the client at any step in the process. Using a client ID number can also help in protecting confidentiality.

Assigning clients *unique* ID numbers enables matching client data even though services have been provided for the same client through different facilities. Countries with established and functioning national ID numbers can use them as the unique ID numbers for the clients. In countries lacking such national ID numbers, a system for providing unique ID numbers for a large geographic area can be developed. The box below provides an example of a unique identifier based on administrative units. Methods such as unique ID number are vital when data processing is centralized.

#### **Example of Unique Identification Number**

Each new woman screened for the first time is assigned a unique 12-digit number:

- Digits 1–2 represent the region/province/state.
- Digits 3–4 represent the district.
- Digits 5–6 represent the health facility code of the primary screening visit.
- Digits 7–8 represent the last digits of the screening year.
- Digits 9–12 represent the sequential number of the patient.

This same number should be used at each visit and is written on the patient's ID card (see Appendix 9.1).

# **Types of Health Information Systems**

A fully computerized HIS is the most effective way to monitor and evaluate programs. Ideally, the system uses unique patient identifiers as well as call and recall mechanisms, and it is linked to population-based cancer registries. Highly sophisticated computerized information systems use computer networking to link facilities. But there are many other types of computerized HISs with varying levels of sophistication. The computerized HIS links various health facilities, laboratories, and data processing centers, so it can easily generate periodic automated reports on key indicators such as coverage, client treatment, and follow-up rates for the entire program. Even for this type of HIS, however, client information will still need to be gathered using handwritten client records and registers. Countries with limited resources may need to rely initially on client records and registers and gradually expand their capability for processing client and program data by using computers.

In this section, we present two types of HIS:

- A facility-level HIS that is based on registers and maintained at the facility.
- A relatively simple, centralized HIS that has all the features of the facility-based HIS. Additionally, it uses stand-alone computers for data processing as well as mechanisms (e.g., unique ID number) to "match" individual client data even though services were provided at different facilities. In this infor-



If funds allow, a computer-based HIS is the most effective way of collecting data for monitoring and evaluating a program.

mation system the data processing is centralized at the subnational level (region/state/province/district), therefore data analysis is possible for the program at the respective subnational level.

Infrastructure requirements will vary according to the kind of HIS put in place and as noted in Chapter 5, funds should be allocated appropriately for establishing and maintaining an HIS. This section provides information that will help management teams determine which system to use in their programs given the available resources. Sample register or forms for both types of HIS are provided in the appendix, and these can be adapted according to the program's data management protocol.

#### **Facility-level health information system**

A facility-level HIS is used to monitor and evaluate the specific services provided at the facility. It can also provide a broad cross-sectional picture of program quality. Though computers may be available at some secondary- and tertiary-level facilities, and can be used for data storage and facility-level data processing, a facility-level system relies largely on registers to collect and aggregate data. Appendices 9.2A to 9.2C provide examples of the following registers:

- Attendance register at the screening level (Appendix 9.2A). This register records basic information and test results on all screened clients. It helps to monitor when laboratory results are missing (when applicable) and to identify patients with test-positive results, requiring further investigation or treatment.
- Laboratory register (Appendix 9.2B). This register is located at the laboratory level to record all the incoming samples (HPV, cytology, or histology) and record results after processing. It helps to monitor results not yet reported to the referring facility.
- Attendance register at the referral level (Appendix 9.2C). This register records all clients coming for diagnosis/treatment services after a positive screening test. It helps to monitor treatment rates according to diagnosis.

At each facility, relevant client information gathered from the registers is used to calculate monthly statistics on a limited number of indicators that are feasible for a facility-level HIS (see Table 9.3). The monthly statistics are recorded on a data collation sheet (Appendix 9.2D). Monthly statistics from the various facilities within a district can then be aggregated to assess the program performance at the district level.

A facility-level HIS can be set up even in limited-resource settings and is relatively easy to use. It can provide aggregate data for comparing performance on a monthly basis and detect marked changes in indicators at each facility. However, it is often difficult to collate all the information pertaining to each and every client, especially when cervical cancer prevention services are provided through several facilities (e.g., referral for diagnosis and/or treatment of precancer) or requires laboratory support. One way to address this issue is to conduct periodic studies, looking at particular aspects of the program. For example, it may be useful to evaluate a cohort of test-positive women to assess their treatment status six months after screening. In spite of its limitations, a well-maintained and functioning facility-level HIS is far better than having no data, poor-quality data, or late data.

**TABLE 9.3.** Using a facility-level HIS to calculate performance indicators

Level of data aggregation	Program elements	Calculating indicators
Screening facilities	Client participation*	Number of women newly screened.
	Appropriate target age group*	Divide number of women screened in the target age group by total number of newly screened women.
	Visual inspection test quality*	Divide number of women with positive test by number of women screened.
Laboratory facility	Cytology quality*	Indicator 1: Divide number of inadequate smears by total number of smears taken. Indicator 2: Divide number of abnormal smears by total number of adequate smears taken.
	HPV DNA test quality*	Divide number of HPV-positive tests by number of HPV DNA tests processed.
	Laboratory processing time	Divide number of test reports (results) sent back to facility within three weeks of receiving the specimen in the laboratory by total number of tests received at the laboratory.
Diagnostic and treatment facilities	Diagnostic (colposcopy), if included in program	Divide number of high-grade lesions detected by number of women who had colposcopy.  Note: Quality of colposcopy can also be assessed by looking for correlation between colposcopy findings and histology findings. This, however, requires linkages with the laboratory.
	Treatment of test-positive women or women with high- grade lesions**	Divide number of women treated by number of women who test positive or who have high-grade lesions.
	Post-treatment complication**	Divide number of post-treatment complications by number of women treated.

<sup>\*</sup> While all elements are important, programs with limited resources should place special emphasis on these elements.

#### Data flow between health facilities

Where services rely on a single-visit approach, client tracking and program monitoring is simplified, since most data can be collated at a single facility. Where services rely on a multiple-visit approach, however, special attention must be given to data flow and linkages between health facilities. For example, when screening

<sup>\*\*</sup>Information for treatment and post-treatment complications can be obtained if screening and treatment are provided at the same facility. If screening and treatment are provided at different facilities, it is more difficult to collate such data.

tests require laboratory processing (cytology or HPV DNA), or when referral for colposcopy (with or without biopsy) or for treatment is required, effective data linkages are extremely important. Specifically, there is a need for:

- Clearly defined referral pathways.
- Mechanisms for tracking data about patients who may require referral for further evaluation or treatment.
- Mechanisms for transmitting patient data to laboratories and reporting results back to health facilities and clients.

#### Tools to facilitate data linkages between health facilities

Lists and registers for establishing and maintaining linkages between health services, laboratories, and the community should be developed. Some examples are given below, all of which are based on the registers described above (Appendices 9.2A–9.2C):

- List of screened-positive patients. Based on test-positive patients flagged in the attendance register (Appendix 9.2A), this list should be generated monthly to facilitate their follow-up. These patients can also be tracked through the "tickler box" system described in Chapter 6 (p. 91).
- List of pending results in the laboratory. A list of the samples sent to the laboratory for which no result has been received within one month should be created at the screening facility and sent to the laboratory for action. This list can be developed based on the date the sample was sent (see Appendix 9.2A).
- List of patients to be recalled for one-year follow-up. A list of patients who received treatment and have not been seen after 13 months should be generated monthly at the treatment facility to facilitate their follow-up. This list can be developed based on Appendix 9.2A or 9.2C.
- Client contact information questionnaire/tracking information. These information forms should be completed and filed in the clients' records and updated at each visit. Keeping these forms current helps to document and ensure a variety of contact sources and information for the client. The forms should include the client's name, address/location of residence and nearest landmark, and work contact information. They can also include contact sources such as close relatives or close friends, as considered appropriate by the client.
- Tracking form for community health workers (CHWs). This form is used for each client being tracked and should include her name, facility name, and contact information. It also contains the date of a scheduled appointment (from register in Appendix 9.2A). The CHW can use this form to document the outcome of any home visit, record when a client is unable to be contacted, indicate whether a client is accepting or refusing to use services, and the reason for not using them.

#### **Centralized health information system**

The decision to implement a centralized, computerized HIS should be based on local conditions and resources. The centralized HIS presented here is based on ACCP experience in Ghana, Guinea, India, and Thailand, and can be established in limited-resource settings. A centralized, computerized cervical cancer prevention HIS can be established for the geographical area (e.g., district, state) in which most services are to be provided. More complex, population-based systems at the national level are possible, if resources permit, but are not described due to their sophisticated requirements.

In a centralized HIS, information gathered using client forms at the facility is fed into a centralized (regional-, state-, or district-level) computer. Using computers enables better data storage, easier and quicker data processing, and production of automated reports on key program indicators. In addition, it is vital that a centralized system has the mechanism to provide unique client ID numbers or codes to enable matching client information from various facilities providing cervical cancer prevention services to the same client (e.g., from the screening facility, the treatment facility, and the laboratory). A centralized system facilitates efficient data processing and assessment of program outcomes. Even when centralized HIS is used, facility-level HIS should be used to assess performance at the facility and institute corrective action.

Having a centralized, computer-based HIS is an advantage since it allows tracking of clients needing treatment and post-treatment follow-up (even when services are provided through different facilities), efficient data analysis, and monitoring and evaluation of process and outcomes of the program. Such an HIS requires well-functioning communication links between the various facilities and the data processing center, as well as availability of computers, power supply, and skilled operators—some of which might not be feasible in many limited-resource settings.

#### Forms and flow of information

Data for a centralized HIS is collected using five standard client management forms (Appendices 9.3A-9.3E). These forms are completed by service providers during each client visit and then sent to a central location for the HIS. The central location is responsible for maintaining the program's database (i.e., entering the information from the forms into the computer).

These forms have been designed to include the minimal information required for accurate client tracking and program monitoring. They can easily be adapted to the service delivery approach and screening test chosen. Each country may adapt its existing forms to include the key information needed at each step of the program and to be consistent with national cervical cancer protocols. For example in each country, program managers should adapt the forms to the cervical cancer classification system already in use. When using preexisting forms, an effort should be made to highlight the key data needed for client tracking and program monitoring.

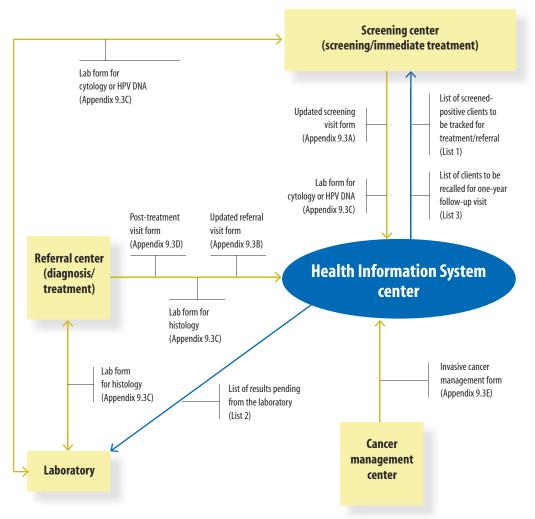
The key information on these forms should also be documented in the client's case notes and/or registers at the screening facility (facility-level HIS). Each form should include a personal information heading. This common section should be repeated at the start of each form in order to ensure the linkage with the patient record in the HIS.

The forms are described below, with instructions for linking the forms to the HIS central location for data entry.

- Screening visit. Form 9.3A should be used for screening and should note action taken. It should be completed after a woman has obtained her test result and action has been taken (i.e., the patient has been reassured, treated, or referred for treatment) based on clinical protocols. This form may require up to three visits to be completed, depending upon the test and the clinical management approach used. A copy of this form should be sent for data entry after the test result visit, or one week after the date of the test result appointment if the woman did not come back to get her result. This will allow for better monitoring of women to be recalled.
- Referral visit. Form 9.3B is the referral visit form for diagnosis and/or treatment at a higher level of health care. It also should be completed after one or two visits, depending on the histology requirement. A copy of this form should be sent for data entry after the diagnosis is established or one week after the date of the histology result appointment if the woman did not come back to get her result.
- Laboratory linkage form. In most countries, form 9.3C already exists and can be adapted. This form is linked with 9.3A or 9.3B by the client's unique identifier. This form should be sent together with the specimen to the laboratory and, once returned, it will allow updating of the respective form (9.3A or 9.3B). A copy of this completed form 9.3C should be sent for data entry when sending the specimen to the laboratory, to monitor processing time. Once the result is back from the laboratory, the individual form (9.3A or 9.3B) is updated and 9.3C should be sent to the HIS center for data entry update.
- *Post-treatment visit*. Form 9.3D is used after treatment for side effects or one-year follow-up assessment at the referral level. A copy of this form should be sent for data entry once completed.
- Cancer management visit. Form 9.3E is used for cancer management at tertiary facilities. A copy of this form should be sent for data entry once completed.

The forms and the flow of the information are illustrated in Figure 9.1. A simplified version of the centralized HIS is possible in programs where screening test results are immediately available (see box on page 187).

FIGURE 9.1. Information flow at the district level for a centralized HIS



#### **Notes:**

Yellow arrows represent an exchange of forms.

Blue arrows represent list generation for performance improvement.

Samples of all the forms are in the Appendix 9.3.

Lists are described on the following page.

A detailed description of the flow of forms and lists begins on p. 188.

For tests needing laboratory processing (cytology, HPV DNA, and histology), screening visit forms and referral visit forms will need to be updated with the laboratory results.

All completed and updated forms are sent to the HIS center.

#### **Simplification of the Centralized Health Information System**

A simplified version of the centralized HIS can be used in some settings where the results of the screening test are immediately available. Testnegative women are counted only to assess participation and form 9.3A is not filled in for women with negative tests. Forms 9.3A to 9.3E are only filled in for test-positive women. All the information (forms for women with positive tests and number of women with negative tests) is still entered into a centralized computer, but data quantity is highly reduced. For example, assuming a screen postivity rate of 10% and screening rate of 100 women in a day, a centralized HIS requires completion of 100 forms 9.3A daily. In contrast, a simplified HIS requires completion of 10 forms (women with positive tests) and simply reports the total number of women with negative screening tests (90).

#### Data entry and report generation

Data should be entered into the computer as soon as forms arrive from the different facilities and laboratories. The data on these forms should be accurate and complete to ensure the reliability of the resulting data outputs. The data manager should generate a periodic report to identify possible inconsistencies in the data records already stored. This report will list records with possible inconsistencies on each form type. Program personnel should validate these data to ensure that they are correct, particularly at the start of the program.

A report should be produced quarterly at the central location of the HIS (see Appendix 9.4) and sent to the different facilities and stakeholders to evaluate progress toward program targets. By comparing the data of the last three months with data from earlier periods (depending on how long the program has been in place), it will be easier to detect marked changes in some key indicators and take appropriate corrective action if needed.

The list of clients requiring recall or referral will be automatically produced and sent to the relevant centers for proactive follow-up (see Figure 9.1):

- List of test-positive clients to be tracked for treatment/referral (List 1).
- List of results pending from the laboratory (if test sent to the laboratory more than four weeks prior) (List 2).
- List of clients to be recalled for one-year follow-up (for those not seen after 13 months) (List 3).

# **Cancer Registries**

The effectiveness of a cervical cancer prevention program is evidenced by the reduction of the incidence and the mortality rates from cervical cancer. Rate changes may be monitored by a population-based cancer registry (Cooke et al. 2002). Cancer registries can also be linked to a centralized HIS, to assess if women who previously screened negative develop cancer, in order to indicate false negative results. It should be noted, however, that while cancer registries are highly desirable, their development and sustainability in low-resource settings may be challenging. Information on how to set up population-based cancer registries can be obtained from the Descriptive Epidemiology group in IARC (www.iarc.fr).

#### **Conclusion**

Proactive monitoring of routine service provision, accompanied by corrective action as needed, is fundamental to good program performance. An HIS based on valid and measurable indicators—facility-level or centralized computer-based HIS—is an essential tool for monitoring and evaluating program performance and generating lists of clients who need to be tracked for treatment or follow-up care. Regardless of which type of HIS is used, good-quality data is essential. In fact, data quality is preferable to quantity. To ensure timely exchange of data and quality information, it is important to designate a staff member responsible for establishing and maintaining communication linkages between health facilities, distributing forms and dispatching reports, and gathering data. In addition to the HIS, qualitative tools and approaches should be used to measure quality of services and less-tangible aspects, such as client satisfaction, that affect utilization of services and thus affect program performance. Such activities have to be done on an ongoing basis at the facility level, involving all facility staff and solving local problems using local solutions.

# **Further Reading**

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Marrett LD, Robles S, Ashbury F, et al. A proposal for cervical screening information systems in developing countries. *International Journal of Cancer*. 2002;102(3): 293–299.

Pan American Health Organization (PAHO). *Model of an Information System for Cervical Cancer Screening Programs in Developing Countries*. Washington, D.C.: PAHO; 2002[b].

World Health Organization (WHO). *National Cancer Control: Programmes, Policies, and Managerial Guidelines*. 2nd ed. Geneva: WHO; 2002[a].

# **Appendix 9.1. Sample Client Identification Card**

[Front view]

Client information
Individual ID [ ][ ] [ ][ ] [ ][ ] [ ][ ]
Region District Facility Year Individual  Name:
Traine.
Date of birth: [ ][ ] / [ ][ ][ ][ ] or Estimated age at last birthday: [ ][ ]  Contact Information (Address, phone, etc.)
Updates (if required)

# [Rear view]

Client follow-up record				
Past visit			Next appointment	
Date	Test/treatment/procedure performed Clinical record number	Place/Clinic	Date	Place

Appendix 9.2A. Sample Attendance Register at Screening Level

 $<sup>^{\</sup>star}$  Only for test requiring laboratory processing (HPV DNA, cytology).

<sup>\*\*</sup> Identify (special color, underline) positive test result.

<sup>\*\*\*</sup> Insert check mark if result given.

<sup>\*\*\*\*</sup> A tracking card in the tickler box should be filled out for all referred clients.

Comments Date result reported Specimen result Specimen processed by Client ID Appendix 9.2B. Sample Laboratory Register Specimen referred from Date sample received Laboratory ID 10 # 7 m 4 5 9 7 **∞** 6

Appendix 9.2C. Sample Attendance Register at Referral Level

/date of ment					
Action taken/date of next appointment					
Diagnosis					
Provider name					
Screening test Provider result*					
Client address					
Age					
Client name					
Client ID					
Referring center					
Date					

m

\*Reported from the screening center (see client's ID card).

### **Appendix 9.2D. Sample Monthly Data Collation Sheets**

#### **Screening facilities**

Month: \_\_\_\_\_ Facility name: \_\_\_\_\_

Indicator	
Number of women screened = (A)	
Number of women out of the target age group = (B) Rate of women out of the target age group = (B/A)	
Number of women with positive test result = (C) (Test-positivity threshold = HSIL or above for cytology) Test-positivity rate (C/A)	
Number of treatments provided (if applicable) = (D) Rate of treatment = $(D/C)$	
Number of women referred for diagnosis/treatment = (E) Rate of referral = (E/C)	

#### **Laboratory facilities**

Month: \_\_\_\_ Facility name: \_\_\_\_

Indicator	
Number of samples processed = (A)	
Cytology	
Number of inadequate smears = (B)	
Rate of inadequate smears $=$ (B/A)	
Number of smears $HSIL$ or above = $(C)$	
Positivity rate for cytology = $(C/[A-B])$	
HPV DNA testing	
Number of HPV-positive samples = (D)	
Positivity rate for HPV DNA testing = $(D/A)$	

#### Diagnosis/treatment facilities

Month:	Facility name:	

Indicator	
Number of women seen = (A)	
Number of women with high-grade lesion diagnosis = (B)	
Detection rate of high-grade lesions = $(B/A)$	
Number of women treated = (C)	
Number of high-grade lesions treated = (D)	
Treatment rate for high-grade lesions= (D/B)	
Number of visits for complications within one month = (E)	
Rate of complications = $(E/C)$	

# Appendix 9.3A. Sample Form for the Screening Visit

	Client informa	tion			
Individual ID  Name:	[ ][ ] [ ][ ] [ ][ ] Region District Facility	Year Individual			
Date of birth: [ ][ ] / [ ][ Contact Information (Ad		mated age at last birthday	:[][]	]	
Center name and code			[	][	]
Date of the visit		[ ][ ]/[ ][ ]/[ ]	[ ][	][	]
Clinical file reference					
Previously screened (1: Yes	s, 2: No, 3: Do not know	)		[	]
HPV DNA/cytology sample	e taken (1: Yes, 2: No) [	Complete the laboratory for	rm]	[	]
Laboratory specimen ident	ification				
Date of the test result appoint the test result appoint the MPV DNA/cytology [keep		[ ][ ]/[ ][ ]/[ ]	[ ][	][	]
Screening test result (use o	only the row correspon	ding to the test used)			
VIA/VILI result (0: Not o	lone, 1: Negative, 2: Posi	itive, 3: Suspect cancer)		[	]
HPV DNA result (0: Not	done, 1: Negative, 2: Pos	sitive)		[	]
Cytology result (0: Inadequate, 1: Norma 6: Invasive carcinoma, 7:		SCUS, 4: LSIL, 5: HSIL, lescribe		[	]
policy, 2: Treatment by cryo	otherapy, 3: Referred for	d designated by national or diagnosis/treatment at the gement, 5: Other, describe _	secon	am dai	ry
If referred, referral center n	ame and code		_ [	][	]

# Appendix 9.3B. Sample Form for the Referral Visit

	Client inforn	nation			
Individual ID  Name:	[][] [][] [][ Region District Facili				
Date of birth: [ ][ ] / [  Contact Information (A		stimated a	ige at last b	irthday: [	][ ]
Center name and code				_	[][]
Date of the visit			][ ]/[ ][	]/[][	][ ][ ]
Clinical file reference Colposcopy result (0: Not done, 1: Normal, 2 HPV change, 4: CIN2–3,	2: Inflammation, 3: Atyp	pia/CIN1/o	condyloma/	/wart/leuk	[ ]
Histology sample taken (1	1: Yes, 2: No) [Complete	e the labor	atory form]		[ ]
Laboratory specimen ider	ntification				
Date of the test result app [keep the form until this o	e.	]	][ ]/[ ][	]/[][	][ ][ ]
Histology diagnosis (recei (0: Inadequate, 1: Normal 5: CIN2, 6: CIN3, 7: Invas 9: Inconclusive)	, 2: Inflammation/cervi	citis, 3: At			
Action taken (1: Reassured and advised policy, 2: Treatment by cr health center, 4: Referred	yotherapy, 3: Referred f	or diagnos	sis/treatmen	it at the se	condary

# Appendix 9.3C. Sample Laboratory Linkage Form

	Client inform	ation							
Individual ID  Name:	[ ][ ] [ ][ ] [ ][ ] Region District Facilit								
Date of birth: [ ][ ] / [ ]	[ ]/[ ][ ][ ] or <b>es</b>	timated a	ige at	last	birth	day:	[][	]	
Contact Information (A	ddress, phone, etc.)								
Part	to be filled by the center re	questing tl	ne anal	ysis					
Center sending the specim	nen (name and code)						[	][	]
Date specimen sent		[ ]	[]/[	][	]/[	[][	][	] [	]
Specimen sent (1: Pap sme	ear, 2: HPV, 3: Biopsy)							[	]
Laboratory specimen iden	tification _								_
Clinical file reference	-								_
Laboratory code								][	
Date specimen received		[][	]/[	][	]/[	][	][	] [	]
Date report sent		[][	]/[	][	]/[	][	][	][	]
Specimen analysis result	(use only the box corre	sponding	to th	e tes	t use	d)			
-	ormal, 2: Inflammation, sive, 8: Other, describe _								ive
HPV DNA test result (0	): Not done, 1: Negative	, 2: Positiv	ve)					[	]
<u> </u>	nal, 2: Inflammation/cer IN3, 7: Invasive squamo onclusive)							[	]
Comments, if any:									-
									_

# Appendix 9.3D. Sample Form for the Post-treatment Visit

	Client information
Individual ID  Name:	[][] [][] [][] [][][][] Region District Facility Year Individual
<b>Date of birth</b> : [ ][ ] / [	] ] / [ ][ ][ ] or estimated age at last birthday: [ ][ ]
Contact Information (A	Address, phone, etc.)
Center name and code	[][]
Date of post-treatment vis	
-	ide effects, 2: One year treatment follow-up)
Clinical file reference	
Fill	in only the part corresponding to the type of visit.
Visit for side effects	
	pain >2 days, 2: Fever > 3 days, 3: Bleeding with passing of oul-smelling discharge, 5: Other)
Diagnosis (1: Healthy cervix, 2: Other	er, describe
	al management (antibiotics, analgesics,), 3: Surgery mer)
One-year treatment follow	-up
Diagnosis (1: Healthy cervix, 2: Oth	er, describe)
	therapy, 2: LEEP, 3: Conization, 4: Hysterectomy, 5: Referred for ent, 6: Other, specify)

# Appendix 9.3E. Sample Form for Invasive Cancer Management

Client information						
Individual ID  Name:	[ ][ ] [ ][ ] [ ][ ] [ ][ ][ ] Region District Facility Year Individual					
Date of birth: [ ][ ] / [ ]  Contact Information (A	]/[][][] or estimated age at last birthday: [][] ddress, phone, etc.)					
Center name and code						
Clinical file reference						
Date of the visit	[ ][ ]/[ ][ ]/[ ][ ]					
Final diagnosis (1: Invasive cancer, 2: Othe	er, describe)					
Stage (1: Stage IA, 2: Stage IB, 3: 8: Stage IVB)	[ ] Stage IIA, 4: Stage IIB, 5: Stage IIIA, 6: Stage IIIB, 7: Stage IVA,					
Histology: (ICD-O code)	[ ][ ][ ][ ]					
Treatment type (1: Radical	, 2: Palliative) [ ]					
	by, 3: Surgery and radiotherapy, 4: Radiotherapy and					
Completion of treatment? (1: Yes, 2: No, give reason						

### **Appendix 9.4. Examples of Reports**

Screening (overall and by testing center)

Last three-month period			Overall			
Average number of screenings per month						
Numb	er:		Numb	er:		
	Age group distribution of the screened women					
Age group	Number	%	Age group	Number	%	
<30			<30			
30-39			30-39			
40-49			40-49			
>50			>50			

Screening test result (depending on the test used)						
Positivity rate (H	IPV DNA <b>,</b> VI	[A, VILI):%	Positivity rate (HPV DNA, VIA, VILI):%			
Cytology result				Cytology result	:	
Result	Number	%	Result	Number	%	
Inadequate			Inadequate			
Normal			Normal			
Inflammation			Inflammation			
ASCUS			ASCUS			
LSIL			LSIL			
HSIL			HSIL			
Invasive carcinoma			Invasive carcinoma			
Inconclusive			Inconclusive			
Other			Other			

		Action ta	ken (only for positive)		
Action taken	Number	%	Action taken	Number	%
Reassured			Reassured		
Cryotherapy			Cryotherapy		
Referred for diagnosis/ treatment			Referred for diagnosis/ treatment		
Referred for cervical cancer management			Referred for cervical cancer management		
Other			Other		

# Referral visit (overall and by referral center)

Last th	ree-month per	iod		0verall	
		Compliance	with referral		
Number of patier a referral visit wi Percent among so	thin 3 months	:	Number of patie a referral visit w Percent among s	ithin 3 month	
	Co	onfirmed precance	rous lesion or cancer		
Number of patier lesion or cancer of Percent among re	confirmed:		Number of patie lesion or cancer Percent among r	confirmed: _	
		Action	taken		
Action taken	Number	%	Action taken	Number	%
Reassured			Reassured		
Cryotherapy			Cryotherapy		
LEEP			LEEP		
Referred for cervical cancer management			Referred for cervical cancer management		
Other			Other		

# Side effect visit (overall and by referral center)

Last three-month period	Overall
Number of sid	e effects visits
Average number of side effect visits per month: Percent of treated patients:%	Average number of side effect visits per month: Percent of treated patients:%

### Laboratory report (overall, by laboratory, and by specimen type)

Last th	nree-month p	eriod		Overall	
	Screeni	ng test result (d	epending on the test (	used)	
Positivity rate (F	HPV DNA):	%	Positivity rate (F	HPV DNA):	%
C	ytology result	:	Су	rtology result	t
Result	Number	%	Result	Number	%
Inadequate			Inadequate		
Normal			Normal		
Inflammation			Inflammation		
ASCUS			ASCUS		
LSIL			LSIL		
HSIL			HSIL		
Invasive squamous cell carcinoma			Invasive squamous cell carcinoma		
Inconclusive			Inconclusive		
Other			Other		
Hi	istology resul	t	Hi	stology resul	t
Result	Number	%	Result	Number	%
Inadequate			Inadequate		
Normal			Normal		
Inflammation/ cervicitis			Inflammation/ cervicitis		
Atypia			Atypia		
CIN1/HPV infection			CIN1/HPV infection		
CIN2			CIN2		
CIN3			CIN3		
Invasive squamous cell carcinoma			Invasive squamous cell carcinoma		
Invasive adenocarcinoma			Invasive adenocarcinoma		
Inconclusive			Inconclusive		
Other			Other		
		Time require	ed for reporting		
Average time for sent to date speci			Average time for sent to date speci		

### One-year treatment follow-up (overall and by referral center)

Last th	ree-month pe	riod		Overall	
		Diagnosis at	t follow-up		
Number of follow- Percent among wo follow-up:	men eligible f		Number of follow Percent among w follow-up:	omen eligibl	
		Diagnosis at	t follow-up		
Diagnosis	Number	%	Diagnosis	Number	%
Healthy cervix			Healthy cervix		
Other			Other		
		Action	taken		
Action taken	Number	%	Action taken	Number	%
None			None		
Cryotherapy			Cryotherapy		
LEEP			LEEP		
Cold knife conization			Cold knife conization		
Hysterectomy			Hysterectomy		
Referred for cervical cancer management			Referred for cervical cancer management		
Other			Other		

### Cancer management (overall and by center)

Last th	ree-month p	eriod		Overall	
		Confirmed	cancer cases		
Number of confirm Percent among wor cancer: %			Number of confirm Percent among wor cancer: %		
		Cance	er stage		
Stage	Number	%	Stage	Number	%
IA			IA		
IB			IB		
IIA			IIA		
IIB			IIB		
IIIA			IIIA		
IIIB			IIIB		
IVA			IVA		
IVB			IVB		
Unknown			Unknown		
		Trea	tment		
Treatment	Number	%	Treatment	Number	%
Surgery			Surgery		
Radiotherapy			Radiotherapy		
Surgery and radiotherapy			Surgery and radiotherapy		
Radiotherapy and chemotherapy			Radiotherapy and chemotherapy		
Other			Other		

Four



**Chapter 10** provides an overview of the clinical and programmatic aspects of cervical cancer treatment and palliative care in order to improve linkages between prevention and control services and to improve access to treatment and palliative care services.

# **Cancer Treatment and Palliative Care**

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#### **Key Messages**

- Countries with *no* cervical cancer treatment services should focus on establishing and strengthening prevention efforts and palliative care services and planning investment in centralized basic treatment services for cervical cancer.
- Countries with *limited* cervical cancer treatment services should focus
  on establishing and strengthening prevention efforts and palliative care
  services, while also improving access to radical surgery (if such potential exists) and radiotherapy services.
- Cervical cancer prevention services should be linked with cervical cancer treatment and palliative care services and integrated, wherever possible, into a national cancer control plan.
- Information and education (I&E) activities should create awareness for both providers and clients that cervical cancer is frequently curable with appropriate treatment.
- Palliative care services should be available at all levels of health facilities, including community-level care.
- In addition to management of pain and other cancer symptoms, palliative care includes providing support at the community level to mobilize local resources, establishing links to treatment centers, and offering additional emotional, social, and spiritual support to terminally ill women and their caregivers.
- Drug regulation and medical/pharmaceutical policies may unnecessarily restrict access to appropriate medications, particularly in rural areas. These policies should be evaluated and revised.

#### Introduction

It is inevitable that a cervical cancer prevention program will identify women with invasive cancer. Cervical cancer is often curable if detected and treated in its early stages: more than 80% of the women detected with early-stage disease can be cured with treatments such as surgery or radiotherapy. The purpose of this chapter is to provide basic information for the management team on the clinical and programmatic aspects of diagnosis and treatment of cervical cancer, including palliative care. The aims are to improve access to treatment and palliative care services and to establish and maintain effective linkages between prevention and treatment services, information systems, and cancer registries.

#### The Role of the Management Team

The management team's role involves coordinating cervical cancer prevention services with cancer treatment and palliative care services. To fulfill this task, the management team should work closely with policymakers and professionals involved in cancer treatment to:

- Ensure functioning linkages are established and maintained among communities; facilities providing prevention, cancer treatment, and palliative care services; and cancer registries.
- Develop strategies for building community awareness of the importance of early detection of cervical cancer.
- Actively participate in the development of strategies to ensure availability and access to cancer treatment and palliative care services.

#### **Background**

#### **Burden of disease**

In many developing countries, a large proportion of cervical cancers are diagnosed in late stages, when treatment is less effective in controlling disease (see Table 10.1 for country-specific data and Appendix 10.1 for an explanation of stages). This burden of disease exists in large part because in those countries there are little or no screening and treatment services available. In contrast, in developed countries the majority of cervical cancer cases present at an earlier stage. Late presentation and limited access to appropriate treatment services result in lower survival rates in developing-country populations (Sankaranarayanan et al. 1998).

**TABLE 10.1.** Distribution of early cervical cancer cases in selected populations in developing and developed countries

City/country	Study period	Total women with cancer	Proportion of women presenting with early stage (localized) cancer
Cuba	1988–89	831	24.1%
Mumbai, India	1982–86	8,861	11.7%
Chennai, India	1984–89	6,141	6.8%
Rizal, Philippines	1987	937	5.2%
Chiang Mai, Thailand	1983–92	3,231	20.7%
Kampala, Uganda	1995–97	261	14.6%
SEER (USA)*	1992–98	7,594	54.0%

<sup>\*</sup>Surveillance, Epidemiology, and End Results Program.

Sources: Sankaranarayanan et al. 1998, SEER 2002.

#### Availability of services in limited-resource settings

The management of invasive cervical cancer continues to be a major challenge in many developing countries, particularly in sub-Saharan Africa, due to the lack of surgical facilities, skilled providers, and radiotherapy services (Stewart and Kleihues 2003). For instance, in many countries in the region, histopathological services are extremely limited or unavailable. Radiotherapy services are rare. Further, the entire African continent has fewer radiotherapy machines than there are in Italy alone. There is only an extremely limited capability for performing radical hysterectomy in the public health services. In some countries, cervical cancer treatment is available in the private sector, but this option is financially prohibitive for the majority of women.

#### Barriers in countries with limited cervical cancer treatment services

The main barriers to the diagnosis, treatment, and management of cervical and other cancers in countries with limited cancer treatment services are:

#### For clients:

- Lack of public awareness about early detection and treatment of invasive cancer
- Association of cancer with death.
- Geographic barriers (transport, roads).
- Economic barriers (inability to pay for health services or other illness-related expenses).
- Sociocultural barriers (reflecting varying patterns of accessing health services).
- Physical (e.g., too ill) and psychological (e.g., depression) barriers related to the disease.

#### For providers:

- Lack of awareness about early detection and treatment of invasive cancer.
- Lack of functioning equipment and short supply of chemotherapeutic drugs.
- Lack of trained personnel.
- Lack of documentation of essential information on client care.
- Lack of linkages among health facilities.

In many countries with cervical cancer treatment services, patients often do not use these services, do not complete their course of treatment, and do not attend follow-up for clinical monitoring. For example, a survey in six premier cancer hospitals in India indicated that a quarter of cervical cancer patients did not take or complete the prescribed course of treatment, and one-fifth of patients with localized cervical cancer did not seek treatment.

#### Diagnosis and treatment options for cervical cancer

For an overview of cervical cancer, see the box that begins below. Treatment methods include radical surgery, radiotherapy (intracavitary and external beam), and chemotherapy. Appendix 10.2 describes for each method how it is performed, indications for its use, facility and personnel requirements, costs, and length of hospital stay. The strengths and limitations of the various treatment methods are presented in Table 10.2. Familiarity with this information will help the management team to advocate and actively participate in planning and coordinating service delivery, and to develop professional and community awareness strategies.

# Clinical Features, Diagnosis, Staging, Investigations, and Treatment of Cervical Cancer

Clinical features Clinical presentation of invasive cervical cancer depends mainly on the location and spread of the cancer. In the very early stages, when the cancer is limited to the cervix (i.e., localized) patients usually do not observe symptoms or clinical signs. Patients with cervical cancer develop symptoms when the tumor spreads and involves other organs, such as the vagina, urinary bladder, and rectum, and ultimately spreads to distant organs. Some presenting features are foul-smelling, bloody vaginal discharge; abnormal vaginal bleeding; blood in the urine; bowel obstruction (vomiting, abdominal pain, and distension); severe backache; severe anemia; and weight loss. If the cancer spreads to the bladder and rectum, fistulas may form between these organs and the vagina (vesico-vaginal and recto-vaginal fistulas), which result in uncontrolled release of urine or feces through the vagina. These are perhaps the most distressing and difficult symptoms to control.

**Diagnosis** The clinical diagnosis of overt cervical cancer is fairly straightforward. In almost all symptomatic women, a pelvic examination reveals a growth in the cervix and its spread to the vagina and surrounding pelvic tissues. A cytological finding of invasive cancer is insufficient to confirm the diagnosis; the diagnosis of invasive cancer must be confirmed by biopsy and histopathological examination of a tissue specimen.

**Staging** To plan appropriate treatment, assess the response to treatment, and predict long-term survival (prognosis), the extent of clinical spread at the time of presentation must be determined, along with a detailed evaluation of the patient's general health. Determining the extent of the tumor within and beyond the pelvis is referred to as "staging." Staging is done by pelvic examination and certain investigative procedures (see below). The staging system developed by the International Federation of Gynaecology and Obstetrics (FIGO) is the most widely used; stages range from Stage I (early stage) to Stage IV (late, or most advanced). Appendix 10.1 provides details on FIGO stages.

**Investigations** Sophisticated diagnostic tests provide valuable information for planning treatment, but they are extremely expensive and not usually feasible in low-resource settings. These tests assess if other organs have been invaded



by cancer and include visualizing the interior of the bladder (cystoscopy) and the lower part of the rectum and anal canal (proctoscopy), plus chest X-rays of the lungs and X-rays of the kidneys (intravenous pyelogram/ urogram). A full blood count and renal- and liver-function tests are also recommended. Ultrasound, computerized tomography (CT), and magnetic resonance imaging (MRI) may provide additional information, but are not mandatory. Because of the resources required for these tests, in many areas the only feasible approaches to staging are speculum examination, vaginal and rectal examination, and visualization of the anal canal (proctoscopy).

**Treatment** Invasive cervical cancer may be treated by surgery, radiotherapy, or a combination of both, with or without chemotherapy. The size and clinical extent of cancer are the most important considerations in deciding treatment. Surgical treatment (radical hysterectomy) performed by trained, skilled, and experienced surgeons is effective management for early stages of cervical cancer. Radiotherapy involves using ionizing radiation to destroy cancer cells and can be used to treat early as well as late stages of cervical cancer. Radiotherapy can be provided in two ways: intracavitary radiotherapy (also known as brachytherapy) or external beam radiotherapy (teletherapy). Brachytherapy is an essential component of radiotherapy of cancer of the cervix. The strengths and limitations of the treatment methods are presented in Table 10.2. Chemotherapy is not used as a primary line of treatment for cervical cancer. Effective management of women with cervical cancer requires a multidisciplinary approach involving gynecologists, radiation oncologists, medical oncologists, pathologists, medical physicists, technicians, nurses, and counselors. (See Appendix 10.2 for key features of the methods to treat cervical cancer.)

**Follow-up care** Women are usually advised to have periodic clinical follow-up after treatment for at least two to five years to assess response to treatment and to detect recurrences, if any, at the earliest possibility. Physical examination of the cervix, vagina, and rectum is carried out during follow-up visits to assess if the disease has totally resolved, is persisting, or if there are features of recurrence or distant spread. In many developing countries, however, there is only limited scope for providing any effective therapy if residual or recurrent disease is detected at clinical follow-up.

**Prognostic factors** Clinical stage of disease at presentation is the single most important predictor of long-term survival. Recurrences more than five years after treatment are extremely rare. Hence, five-year survival is a good indicator of cure. When treated appropriately, five-year survival:

- Exceeds 80% for patients with Stage I disease.
- Exceeds 70% for patients with Stage IIA disease.
- Is about 40 to 50% for patients with Stage IIB and Stage III disease.
- Is less than 10% in patients with Stage IV disease.

Source: Sankaranarayanan 1995, Sankaranarayanan 1998.

 TABLE 10.2. Strengths and limitations of cervical cancer treatment methods

Chemotherapy	<ul> <li>Can be combined with radiotherapy for the management of locally advanced cancer.</li> <li>Can be used in the management of very advanced cervical cancer.</li> </ul>
Radiotherapy	<ul> <li>Used in the treatment of all stages of cervical cancer as well as other kinds of cancer (e.g., breast, head, and neck).</li> <li>Effectiveness varies with the stage of the disease.</li> <li>Radiotherapy is the only realistic treatment once the disease has spread beyond Stage IIA, when surgery is neither feasible nor effective. It is commonly used for less extensive tumors when surgical expertise is not available.</li> <li>Survival rates are equal to surgery in early-stage cancers.</li> <li>Suitable alternate option for women with early disease but at high risk for surgery.</li> <li>Mainly provided as an outpatient/ambulatory service.</li> <li>High dose-rate machine for intracavitary treatment can treat 1,000–2,000 patients per year and can also be used to treat other cancers (e.g., head and neck, breast, brain, rectum, prostate). The unit cost per patient treated decreases the more the machine is used.</li> </ul>
Radical surgery	<ul> <li>Surgery performed by skilled and experienced surgeons is effective in the treatment of early stage (Stage I and selected Stage IIA) disease.</li> <li>Allows preservation of ovaries in young women and avoids vaginal stenosis (narrowing).</li> <li>Limited capital investment is required for development of surgical services compared to radiotherapy services.</li> </ul>
Features	Strengths

Features	Radical surgery	Radiotherapy	Chemotherapy
Limitations	<ul> <li>The role of curative surgery diminishes in patients with cervical cancer that has spread beyond the cervix into the surrounding tissues.</li> <li>Requires skilled and experienced gynecologists.</li> <li>Requires a stay in the hospital (10–14 days).</li> <li>Complications include pelvic sepsis, pelvic thrombosis, and postoperative pneumonia. Ureterovaginal or vesicovaginal fistula can occur as a postoperative complication in &lt;1% of patients.</li> </ul>	<ul> <li>Requires trained and skilled radiation oncologists, medical physicists, and radiotherapy technicians to provide the treatment and to operate and maintain the equipment properly.</li> <li>Requires expensive equipment and supply of radioactive sources. Service contracts and spare parts are also necessary.</li> <li>If utilization is low, the cost per patient increases since the machine must be maintained and the radioactive source changed periodically, regardless of how many patients are treated.</li> <li>Requires a reliable power supply.</li> <li>Acute side effects include radiation-induced inflammation of the rectum (proctitis) and urinary bladder (cystitis). Late complications, such as bowel obstruction and rectovaginal and vesicovaginal fistula formation, may occasionally occur.</li> <li>Low dose-rate brachytherapy requires an operating room and anesthesia services to place the intrauterine catheter and vaginal ovoids. However, this machine can only be used to treat gynecological cancers.</li> </ul>	Requires trained and experienced medical oncologists.     Chemotherapeutic agents are expensive, making them inaccessible and not widely available in many countries.     Not effective as first-line treatment.

# Strategies to Establish and Strengthen Cervical Cancer Treatment Services

Provision of cervical cancer treatment requires careful planning and organization, involving key stakeholders and personnel with expertise in cervical cancer treatment. Policymakers and management teams should make planned, phased investments in cancer diagnosis and therapeutic services as advocated by the World Health Organization (WHO 2002a). Women with cervical cancer will be detected in cervical cancer prevention services, so it is important that prevention services are set up and linked with available cancer treatment services. In countries with no diagnostic and cancer treatment facilities, initial investment should focus on establishing services for clinical diagnosis, histopathology, surgical treatment, and palliative care. Investments in radiotherapy may be considered as a next step once the basic services are developed and stabilized.

Strategies to improve access to cancer care can be carried out at three levels: policy development, management, and community. These strategies will vary depending on the resources available and the political and legislative framework of each country. Although the management team is usually not involved at the policy level, it is useful to understand the policies needed to support cancer treatment services. In addition, the management team may have an important role to play in involving stakeholders and developing community-based advocates.

#### **Policy level**

Providing equal access to treatment for all cervical cancer patients requires establishing social legislation or mechanisms to minimize barriers linked to the cost of treatment. This step requires advocating and involving key stakeholders to prioritize the needs of cancer patients on the political agenda.

Decisions about the mode of treatment are also usually made at the policy level. Technical, programmatic, and cost implications of the various treatment modes are outlined in Appendix 10.2 and Table 10.2 to help with that decision-making. For example, chemotherapeutic drugs are expensive and not widely available in many developing countries. However, purchasing these drugs from manufacturers in other developing countries, such as Brazil, China, India, or South Africa, can be cheaper and thus a more feasible option.

Another important policy development strategy is to develop national protocols for the management of cervical cancer. These protocols should be appropriate for the country's available resources. This strategy involves the following steps:

- Set up a multidisciplinary task force to develop national protocols and periodically revise them.
- Organize meetings to orient and disseminate the protocols to all relevant personnel.
- Ensure that copies of the protocols are available to all relevant health workers.

#### **Management level**

#### Planning and investing in centralized basic treatment services for cervical cancer

While it is feasible to develop surgical services in more than one location within a country at the secondary- and tertiary-care levels, it is best to centralize radio-therapy and chemotherapy services at tertiary facilities. For example, the number of teletherapy (external beam radiotherapy) machines required depends on the age pyramid of the population and the national incidence of cervical cancer. For most developing countries, one machine is the minimum required to provide treatment for a population of about two million people.

#### Setting up radical surgery services

Facilities providing radical surgery should be adequately equipped to provide appropriate preoperative, operative, and postoperative care. Access to blood transfusion services, laboratory services, and a fully functioning operating room with trained and experienced surgeons, anesthetists, and operating room nurses is crucial. Trained and experienced nurses should be available to provide postoperative monitoring and care.

#### Setting up radiotherapy services

As detailed in Appendix 10.2, radiotherapy requires specialized equipment, but it can be used to treat all stages of cervical cancer, and short courses can have a dramatically beneficial effect on localized pain in patients with advanced cancer. Furthermore, radiotherapy units can treat other cancers as well (e.g., head and neck, breast, brain, prostate). Once a radiotherapy unit is set up, the unit cost per patient treated decreases with increased use of the unit.

To assist in deciding on equipment needs, a management team should consider the cost and utility of the equipment. For example, telecobalt machines (see Appendix 6.4) and linear accelerators can be used to deliver external beam radiotherapy. However, linear accelerators provide very little added advantage over telecobalt machines. Cobalt machines are less expensive than linear accelerators, are easier to maintain, have more predictable dose rates, and require only minimal maintenance. Brachytherapy is essential for the radiotherapy of cervical cancer. Having high dose-rate brachytherapy is useful for countries with a large number of patients with cervical cancer, since high dose-rate brachytherapy can be used to treat a large number of patients without the need for general anesthesia or hospitalization. Accessories for radiotherapy, such as devices that assist with developing treatment planning systems, can be introduced once the basic equipment has been installed and services are running.

The International Atomic Energy Agency (IAEA) provides technical and financial assistance upon request from member states for establishing and maintaining radiotherapy services and for organizing training for radiotherapy professionals. Management teams can contact appropriate IAEA personnel through the agency's website (www.iaea.org) or by writing to:

ARBR/NAHU International Atomic Energy Agency P.O. Box 100 A1400 Vienna, Austria

#### **Organizing training programs**

As discussed in Chapter 8, organizing a training program for cervical cancer treatment involves selecting training sites with sufficient caseload, experienced trainers, and appropriate trainees. A training curriculum should be developed based on the national protocols.

In countries that have no cervical cancer treatment services, it is important to organize a training program for a core group of personnel in the essential disciplines related to the diagnosis and treatment of cervical cancer. In-country training is advised in order to demonstrate service delivery skills and approaches in a more realistic manner that trainees can apply in their own sites. Likewise skilled and experienced trainers from countries with similar health care and sociocultural systems are preferred.

In developing countries with the need to expand the capacity of cervical cancer treatment services, it is essential to plan an intensive and focused training program. Skilled and experienced in-country staff can provide the training. In addition, refresher training should be an integral part of all training programs. To enable providers to maintain their skills it is important that trained providers are given the opportunity to perform procedures in facilities with adequate caseload.

#### **Case Study of Cervical Cancer Awareness Campaigns**

In Barshi, India, a gradual improvement in stage distribution and three-year survival was observed following cervical cancer awareness campaigns. In an ongoing community awareness study in the Solapur district, the outcome of a health education program in one subdistrict was monitored for cervical cancer incidence, stage distribution, survival, and mortality, and compared with the outcome in a control area of approximately equal size, with no special intervention. Health education was carried out by person-to-person communication by health workers during house visits and by special group sessions for women in the villages. They discussed various aspects of female genital hygiene, including cervical cancer and its symptoms, and diagnostic and treatment facilities available in the district. Although the incidence was similar in the two groups, stage distribution and mortality was much improved in the intervention group four years after the intervention began (Jayant et al. 1995, Parkin and Sankaranarayanan 1999).

#### Providing patient education and counseling

Patients have the right to be informed about their medical diagnosis and prognosis, the risks and benefits associated with their treatment options, and the facts (why, how often, where to go) about follow-up care. Patients and their families are often overwhelmed by the complex administrative health structure, have difficulties organizing or claiming financial assistance, and are often unaware that such benefits exist. Management teams should be aware of the rules and regulations related to travel concessions and reimbursement policies and should enable patients to access

these benefits. To ensure patients have access to up-to-date information, programs should involve the following steps:

- Develop and make available appropriate, easy-to-understand printed materials in the local language.
- Orient staff at the facilities to provide information about administrative issues, available social assistance to increase compliance with treatment, and places to get medical assistance within a community or local health facility.
- Train health workers on interpersonal communication and counseling skills to improve their rapport with patients and their families.
- Engage community health care workers as communication agents.

#### Updating service providers and health care managers in prevention services

All cervical cancer prevention training programs should include a session on cervical cancer treatment, emphasizing diagnosis, treatment, and prognosis in relation to the stages of cervical cancer. The message that cervical cancer is often curable, if people have ready access to screening and treatment services, should be emphasized.

#### Strengthening health information systems, including cancer registries

It is vital to develop medical record systems to monitor and evaluate the effectiveness of cancer treatment. This process requires the following steps:

- Develop standardized medical records to document information on clinical findings, results of investigations, staging, treatment plans, treatment executed, and response to treatment. Records should also include findings at follow-up, such as date of examination, clinical findings, and disease status.
- Organize regular systematic clinical audits and medical record reviews to ensure complete documentation of clinical information, review management, and improve treatment as necessary.
- Organize hospital cancer registries to collect information on all cancer cases seen. Extract relevant information from the medical records and document it using an appropriate format on an ongoing basis.
- Organize population-based cancer registries to collect information on every person diagnosed with cancer in a defined population on an ongoing basis. The International Agency for Research on Cancer (IARC) provides technical assistance to set up cancer registries. Further information is available on the IARC website (www.iarc.fr). Appropriate personnel can be contacted as follows:

Descriptive Epidemiology Group International Agency for Research on Cancer 150 cours Albert Thomas Lyon 69008 France Email: dep@iarc.fr

#### Decentralizing care of patients with incurable cancer

Health staff at primary- and secondary-level facilities can help patients with incurable cancer by treating the symptoms of advanced disease. They can also link with community health workers (CHWs) to assist in caring for and following up women with advanced cancer (palliative care is discussed in more detail later in this chapter).

#### Establishing and maintaining links to the community and to other health services

Cancer treatment requires coordination, using both inreach and outreach I&E strategies to ensure shared information across settings, between providers, and over time (i.e., from the initial patient contact onward) (WHO 1990). One of the management team's key responsibilities is to establish and maintain links among the various services within a facility—such as inpatient, outpatient, pharmacy, and screening and diagnostic units—and between service sites and other facilities in the community. Collaborating with nongovernmental and other community-based organizations that provide cancer services can offer useful resources to the management team.

Links to the community can be established and maintained by engaging CHWs trained to communicate with patients, accompany patients when they attend treatment, track patients needing follow-up care, and provide support to patients and their families. The principle of setting up links to the community and between other health services is discussed in detail in Chapter 6.

#### **Community level**

Many of the barriers to accessing cancer treatment are due to the prohibitive costs of treatment for patients and their families. The following suggestions to improve access at the community level may require policy-level decisions about funding, which may be outside the management team's mandate.

- Reimbursing patients' travel costs to and from cancer treatment facilities. In India, railway travel concession is provided to a cancer patient and an attendant.
- Providing no-cost or subsidized accommodation where patients can stay to complete treatment (because cancer treatment often requires multiple doses over several days).
- Providing supportive assistance to reduce the social and economic burden of the disease. Social services should be included as a component of oncology services.

Other community-level approaches to increasing access to cancer treatment services can include:

• Providing culturally appropriate services that take into account women's needs. Consider local languages, beliefs, and feelings of patients in service-delivery planning. Health workers should be familiar with the local demographic and social structure, as well as the potential cultural and social barriers to seeking treatment.

- Supporting the patient and her family to provide adequate home care.
   Many physical problems can be prevented or managed by coordinating efforts among the patient, caregivers, and health workers.
- Mobilizing community-based mechanisms will be especially important in areas where there are few social workers. Patient associations or group meetings can be very useful for sharing information and generating advocacy for quality services and social-protection policies.
- Providing patients, their families, and CHWs with simple, precise guides on symptom care, backed up whenever possible with communication links enabling one to "cry for help" when needed.

There is evidence that greater awareness of cervical cancer among health workers and the public can increase early diagnosis of cervical cancer and access to basic treatment, both of which can improve survival (Jayant et al. 1995, Parkin and Sankaranarayanan 1999, Ponten et al. 1995). Trained CHWs can provide health education to individuals and groups, or a combination of both (see box below). Job aids with pictorials should be developed to help health workers provide health education.

#### **Palliative Care**

Palliative care aims to improve the quality of life of patients with terminal illness, through the prevention, early detection, and relief of distressing symptoms and psychosocial problems. It implies not only total care of a person with a debilitating disease not amenable to curative treatment, but also the needs of the family and of the health workers. The main characteristics of palliative care are listed below.

#### **Characteristics of Palliative Care**

#### **Palliative care:**

- Is applicable early in the course of illness, in conjunction with other therapies such as chemotherapy or radiation therapy, and includes tests needed to better understand and manage distressing clinical complications.
- Enhances quality of life, and may positively influence the course of the illness.
- Affirms life and regards dying as a normal process.
- Integrates the psychological and spiritual aspects of patient care.
- Offers support to help patients live as actively as possible until death.
- Provides relief from pain and other distressing symptoms.
- Offers support to help the family cope during the patient's final illness and death and their bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counseling.

#### Types of palliative care services

Palliative care varies from one person to the next, because there are many different stages of disease progression during which the needs of the patient and her family change. Palliative care services include inpatient management of advanced pain and other symptoms, home-based care, and support for family and other caregivers, including psychosocial and spiritual assistance. Thus, both the patient's family and a wide variety of personnel—primary health workers, primary care physicians, nurses, doctors, oncologists, CHWs, and social workers—have roles in providing comprehensive palliative care for the patient with advanced cancer.

#### Holistic management of patients with cervical cancer

An efficient palliative care program should recognize promptly the symptoms of advanced cervical cancer and take adequate measures to provide relief. There are three main components of managing advanced cancer symptoms: pain management, management of other symptoms, and assistance with psychosocial concerns inevitably associated with advanced cervical cancer.

**Pain management** Most women with advanced cervical cancer will experience pain, including severe backache. Pain control can be achieved in most patients with appropriate pain-relieving radiotherapy and/or drugs (see Appendix 10.3).

Management of other symptoms Other symptoms of advanced cervical cancer are vaginal bleeding, foul-smelling vaginal discharge, leg swelling, bowel obstruction, urinary and or fecal incontinence, and bedsores. Table 10.3 provides information on the common symptoms faced by patients, measures that can be used to provide relief, and where these services can be provided. Many symptoms can be managed through simple procedures performed by existing staff and using existing facilities. The management team's task is to determine who can provide these services, where they can provide them, and which clients need to be referred to other facilities or organizations.

**Psychosocial concerns** Assistance with psychosocial issues will require sensitivity to the local culture and the disruption of family life inherent in the patient's changed status. Caregivers must appreciate the philosophy of palliative care, which is briefly summarized in this chapter.

TABLE 10.3. Management of physical symptoms of advanced cervical cancer (information on pain relief is found in Appendix 10.2)

Symptoms	What can be done	Who can provide services	Where to provide services
Vaginal bleeding	<ul> <li>Moderate bleeding: vaginal packs and oral sedatives to relieve anxiety; oral iron.</li> </ul>	Any trained health worker	Primary, secondary, and tertiary facilities
	<ul> <li>Intractable bleeding: short courses of radiotherapy. Either brachytherapy or teletherapy may be used.</li> </ul>	Radiation oncologist	Tertiary facility
Foul-smelling vaginal discharge	<ul> <li>Periodic packing of the vagina with clean cloths soaked with a solution of water and bicarbonate of soda powder (1 Tablespoon in 500 ml water), or table vinegar (1 part vinegar to 4 parts water), or metronidazole solution (5 to 10 crushed 200-mg tablets in 500 ml water). Repeat two times a day for no more than a few hours at a time for five days. Douching can also be done with any of the solutions listed above.</li> <li>A course of antibiotics such as doxycycline (singly) or a combination of amoxicillin and metronidazole.</li> </ul>	Any trained health worker	Home care; primary, secondary, and tertiary facilities

Symptoms	What can be done	Who can provide services	Where to provide services
Leg swelling (lymph edema)	<ul> <li>Raise the legs or wrap with an elastic crepe bandage (not tightly applied).</li> <li>If leg is inflamed, a course of antibiotics (penicillin or erythromycin and anti-inflammatory drugs such as ibuprofen or diclofenac).</li> </ul>	Any trained health worker	Home care; primary, secondary, and tertiary facilities
	<ul> <li>Short course of radiotherapy to the enlarged lymph nodes or chemotherapy.</li> </ul>	Radiation oncologist	Tertiary facility
Severe, colicky abdominal pain with vomiting and abdomi- nal distention due to bowel obstruction	Surgical management most effective.	General surgeon	Secondary or tertiary facility
Urinary and/or fecal	Catheterization of bladder and vaginal packing.	Any trained health worker	Primary, secondary, or tertiary facility
ricontinience due to vesicovaginal and/or rectovaginal fistula	<ul> <li>Surgical management by diverting colostomy and colostomy bags will provide temporary relief.</li> </ul>	Surgeon	Secondary or tertiary facility
Severe anemia	• Oral iron.	Any trained health worker	Home care; primary, secondary, or tertiary facility
	• Blood transfusion.	Health workers (doctors, nurses)	Secondary or tertiary facility

Symptoms	What can be done	Who can provide services	Where to provide services
Bed sores	<ul> <li>Best to prevent by frequently changing position of the patient to relieve specific pressure points on the skin. Daily baths.</li> </ul>	Caregiver: family, community Home member	Ноте
	• Bed sores already developed: have patient lie on a soft mattress and cushion areas with pillows or folded cloth below pressure points. Wash bedsores every day with 2% hydrogen peroxide or povidone iodine. Dust sores with antibiotic powder. Antibiotic courses may be useful.	Any trained health worker	Primary, secondary, or tertiary facility

#### Home care

Family members can act as the primary caregivers, providing palliative care in the patient's own home. In many cases, it is the only option for women living in remote areas. Home care can fail, however, if the informal network becomes too stressed due to disease progression, treatment intensity, or depletion of resources. Thus, providing emotional, social, and instrumental support to families and caregivers is a vital component of palliative care. A CHW can be trained to assess the patient and can promise to be accessible whenever the need arises, visit the patient at home regularly, and provide care, practical help, and emotional support. CHWs can also support those providing palliative care at home, including teaching family members to administer medicines and to use simple techniques to improve the patient's comfort and well-being. Health workers can organize educational sessions on symptom management with patients, families, and other caregivers.

#### **Psychosocial and spiritual support**

Psychological distress is to be expected as patients confront the implications of cancer: pain, dependence on others, disability, disfiguring changes of the body, loss of function, and death—all of which change and sometimes threaten her relationships with others. In many cases, patients experience fear, shock, despair, anger, anxiety, and depression. These feelings can negatively influence the patient's perception of symptoms and her ability to deal with them. Providing emotional, psychosocial, and spiritual support can ease these feelings and improve the patient's quality of life.

#### Ethical issues of providing palliative care

Due to advances in medical technology, the cancer patient's family may be confronted with deciding whether or not to pursue aggressive and expensive treatments (e.g., palliative chemotherapy) to prolong the patient's life. Treatment decisions should always be made with informed consent. Wherever possible, the patient, together with her family and other caregivers, should make these decisions.

#### Strategies to establish and maintain palliative care services

#### Overcoming barriers to implementing palliative care

Providing quality palliative care is challenging in most regions of the world, due to problems associated with availability of medication, deficient health infrastructure, lack of training for providers, lack of counseling skills, discomfort in discussing the diagnosis and management with patients, and lack of community awareness of palliative care options. For example, health workers and policymakers are often unaware that there are inexpensive, effective ways to relieve advanced cancer symptoms.

Over the last few years, however, the role of palliative care has received wide acceptance as an integral part of cancer management early in the course of a fatal disease. Such recognition has improved the lives of millions of patients with chronic, unrelieved pain and with other physical or psychosocial problems. Still, much remains to be done to further improve matters. Where available, specific therapies (e.g., radiotherapy, chemotherapy, pain-relieving drugs) must be used for palliative care

because they have an important role in improving the patient's quality of life. It is also important to work in conjunction with other existing community-based programs. This section describes the key interventions needed to increase access to palliative care in developing countries.

Policymakers' and health workers' lack of knowledge and attitudes are major barriers to providing effective palliative care. Management teams can play an important role in organizing advocacy to ensure that pain medications are accessible (in terms of availability and cost) to women with terminal cancer, particularly those living in remote areas. Table 10.4 describes other barriers to effective pain management.

**TABLE 10.4.** Barriers to cancer pain management

Service provider barriers	Patient barriers
<ul> <li>Health system</li> <li>Low priority given to cancer pain treatment</li> <li>Restrictive regulation of controlled substances</li> <li>Unavailability of treatment</li> <li>Prohibitive drug costs</li> <li>Health professionals</li> <li>Inadequate knowledge of pain management</li> <li>Poor assessment of pain</li> <li>Concern about regulation of controlled substances</li> <li>Fear of patient addiction</li> <li>Concern about side effects of analgesics</li> <li>Concern about patients becoming tolerant to analgesics</li> </ul>	<ul> <li>Concern about distracting physicians from treatment of underlying disease</li> <li>Concern about not being a "good patient"</li> <li>Inability to pay for pain treatment</li> <li>Reluctance to report pain</li> <li>Reluctance to take analgesics or narcotics</li> <li>Fear that pain means disease is worse</li> <li>Concern about becoming tolerant to analgesics</li> <li>Fear of addiction or of being considered an addict</li> <li>Concerns about unmanageable side effects</li> </ul>

#### Interventions to improve access to pain management

Interventions to improve access to pain management care can be considered at both the policy and management levels.

#### **Policy interventions**

Policymakers and health administrators have an important role to play in advocating for an appropriate pain management legislative framework. First, the country's national drug policy should incorporate WHO's essential drug list (WHO 1992), which includes analgesics (pain relievers) appropriate for palliative care. Second, appropriate and fair pricing should be established, along with social legislation to support distribution systems and other mechanisms to ensure access to pain treatment for all patients. In addition, it is vital that regulations are in place permitting physicians, nurses, and pharmacists to prescribe, dispense, and administer opioids to patients according to local needs (WHO 1996).

#### **Management interventions**

WHO publications and guidelines for cancer pain relief and other aspects of palliative care are useful sources of information for organizing pain relief services (WHO 1990, WHO 1996, WHO 1998a, WHO 1998b, WHO 2002a, WHO 2002b). The following are key requisites for health care managers to carry out:

- Ensure the availability of commonly used analgesics. In this respect it is important to allocate resources for procuring, distributing and resupplying appropriate analgesics. Refer to Appendix 10.3 for the list of commonly used analgesics to relieve cancer pain.
- Promote methods to assist health workers in assessing the severity of pain and deciding on treatment, as well as to assess response to pain relief measures. Simple methods such as numbers, words, or visual analogues can be used—for example, using coins of different sizes to prompt patients to categorize the intensity of their pain. Regular documentation of the severity of pain during the course of treatment assists in evaluating analogue.

**FIGURE 10.1.** Visual tool for evaluating pain















- Adopt WHO's three-step analgesic ladder as the treatment protocol. The first step is to use simple, non-opioid analgesics, such as paracetamol or aspirin. If pain is not relieved by a non-opioid analgesic, go to the next step and add a weak opioid, such as codeine or dihydrocodeine. If this fails to relieve the pain, a strong opioid, such as morphine, should be used as the third step. Additional drugs (adjuvants), such as amitriptyline, are used to treat neuropathic or musculoskeletal pain. Anti-inflammatory drugs, such as ibuprofen or diclofenac, are added when the disease affects the bones.
- Ensure that providers are oriented to the pain management protocols and regulatory framework for the use of analgesics. Protocols should emphasize the important principles of use of analgesics for cervical cancer pain relief: providing oral administration of analgesics, using WHO's three-step analgesic ladder to prescribe pain relief, administering analgesics regularly (by the clock), tailoring the dose to meet the patient's needs, and providing clear instructions on the regimen to the patient and her family. In terminal cancer, concerns about addiction are irrelevant. Opioid doses generally increase due to increasing pain as the disease progresses, not because patients develop a tolerance to or a psychological dependence on the medicine.

• Ensure that clear written or pictorial instructions on the drug regimen are developed to give to the patient, her family, and other caregivers.

# Other interventions

# **Ensuring management of other physical symptoms**

Table 10.3 provides information on the measures that can be used to provide relief from other physical symptoms of cervical cancer and where these services can be provided. Where available, palliative radiotherapy can be used to relieve symptoms such as severe bleeding, bone pain due to metastases, and swelling of the legs. Palliative radiotherapy is particularly effective in relieving pain from bone metastases. Radiotherapy departments may reserve special days in the week to provide palliative radiotherapy in order to ensure access for advanced cancer patients. PATH and EngenderHealth's field manuals on the essentials of palliative care are useful sources of reference for all health workers (see Further Reading).

# Improving health workers' counseling skills

It is important that palliative care providers have good communication skills. Training health workers in interpersonal communication and counseling skills to help them discuss cancer and death with patients and their families should be an essential part of all cervical cancer training programs. Training in counseling is essential to help health workers respond effectively to the complex needs of patients for whom a cure is no longer possible.

Many patients have fears and beliefs that make it difficult for them to accept the end of curative care. They feel abandoned and isolated because the medical system has "given up" on them. Health workers should be aware of their important role in giving psychological and emotional support to the patient and her family in this situation. They also have the important role of empowering patients to seek and to accept pain management.

### Home care: steps to support patients, families, and caregivers

Management teams can play an important role in supporting home care for cancer patients by taking the following steps:

- Train and engage community health care workers to provide home-based palliative care and psychosocial support to patients and their families. These types of care should be an essential component of the training provided to CHWs involved in prevention activities. To enable CHWs to provide appropriate care it is important to provide them with job aids, access to essential supplies, mentoring and supervision, and links with staff at appropriate facilities.
- Organize educational sessions on symptom management for patients, families, and other caregivers.
- Organize social networks to help patients, families, and other caregivers cope with the social, emotional, and economic burden of cervical cancer treatment, including regular group meetings to share information and to provide social and psychological support.

• Provide information about available community resources and information on remuneration of transport costs. Useful written information can be accessed from the International Association for Hospice and Palliative Care's web site at www.hospicecare.com.

# Strategies to support psychosocial and spiritual aspects

This support can take many forms, depending on the social and cultural context.

- Group meetings of women with advanced disease are useful because groups encourage emotional learning, relieve anxiety by enabling patients to see how others are coping with the same problems, and encourage the expression of feelings without fear of being ridiculed.
- If available, psychotherapy should be offered as part of the treatment.
- Spiritual counseling is meaningful for many patients as they turn to their religion during the existential crisis brought on by cancer.

For further information on strengthening palliative care services, refer to WHO's National Cancer Control Programmes: Policies and Managerial Guidelines, 2nd edition, and Community Home-Based Care in Resource-Limited Settings: A Framework for Action (and see Further Reading).

# Conclusion

Cervical cancer prevention services should be linked with cervical cancer treatment and palliative care services. From the experience of the ACCP, collaborators, and in-country partners, two overall strategies can be described to reduce the burden of disease from cervical cancer.

For countries with no radiotherapy, radical surgery, or chemotherapy, the focus should be to:

- Establish and strengthen cervical cancer prevention services to reduce the future need for resource-intensive treatment services.
- Establish and strengthen palliative care services at all levels of health facilities, including community care.
- Plan and start investing in centralized basic treatment services for cervical cancer.

For countries with limited cervical cancer treatment services, the focus should be to:

- Establish and strengthen cervical cancer prevention services to reduce the future need for resource-intensive treatment services.
- Establish and strengthen palliative care services at all levels of health facilities, including community care.
- Strengthen and increase the availability of radical surgery, if such potential exists.
- Strengthen and increase access to available radiotherapy services.

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# **Useful** websites

The Edmonton Palliative Care Program: www.palliative.org/

McGill Cancer Nutrition—Rehabilitation Program: www.mcgill.ca/cnr

WHO Palliative Care: www.who.int/cancer/palliative/en

# Appendix 10.1. Technical and Programmatic Aspects of Treatment Options for Cervical Cancer

Features	Radical surgery	Radiotherapy		Chemotherapy
		Intracavitary (brachytherapy)	External beam (teletherapy)	
Description	Major surgical procedure performed under general anesthesia. Involves removal of cervix, uterus (with or without ovaries), parametrial tissue, upper part of the vagina, and lymph nodes in the pelvis. Requires careful dissection of both ureters.	Involves delivery of radiation using radioactive sources in special applicators placed in the cervical canal and vaginal fornices.  • Two types: low dose-rate, e.g., Cesium-137 (treatment takes 1–3 days) and high dose-rate, e.g., Iridium-192 (treatment takes a few minutes)	Involves delivery of a radiation beam to the cancer from an external source, i.e., the teletherapy machine. Telecobalt machines or linear accelerators can be used to deliver external beam radiotherapy.	The most common agents are Cisplatin or Carboplatin given as intravenous (IV) infusions.
Indication	Early stages (Stage I and selected cases of stage IIA).	<ul> <li>All stages, including palliative care.</li> </ul>	<ul> <li>All stages, including palliative care.</li> </ul>	<ul> <li>Advanced stages (in combination with radiotherapy).</li> <li>Palliative care.</li> <li>Recurrent disease.</li> </ul>
Level of facility	Treatment for cancer is centralized and provided in tertiary-level facilities. Radical surgery is possible in some secondary-level hospitals.	d in tertiary-level facilities. level hospitals.		

Features	Radical surgery	Radiotherapy		Chemotherapy
		Intracavitary (brachytherapy)	External beam (teletherapy)	
Personnel required (treatment for cancer is best provided by a multidisciplinary team)	Gynecologists experienced in radical pelvic surgery, anesthetists, pathologists, nurses experienced in a wide range of oncology care, counselors and social workers experienced in psychosocial counseling.	Radiation oncologists, physicists, radiotherapy technicians, nurses experienced in radiation sciences, and oncology care, counselors and social workers experienced in psychosocial counseling.	liotherapy technicians, nurses Id oncology care, counselors and Isocial counseling.	Physicians and nurses experienced in providing chemotherapy, counselors and social workers experienced in psychosocial counseling.
Cost of setting up and maintaining services	An operating theater with necessary equipment and surgical instruments to perform radical surgery can cost about US\$15,000.	Cost of low dose-rate brachytherapy machines (less commonly available) with sources lasting 15–20 years can range from US\$80,000 to US\$300,000. A single machine has a capacity to treat 100 cervical cancer patients per year.  High dose-rate brachytherapy machines (more commonly available), including a 5-year supply of sources at 4-month intervals, cost about US\$250,000. Thereafter US\$35,000 is required annually. Each machine can treat up to 1,000–2,000 patients per year making them more cost-effective in a centralized service.	Telecobalt equipment can cost about U\$\$350,000, and the source needs to be changed every 5–7 years at a cost of U\$\$80,000. During its 20–25-year lifespan, each machine can treat 20,000–25,000 patients.  Linear accelerators are more expensive to purchase and maintain (cost about U\$\$1,000,000 to purchase depending upon the energy range and availability of electrons). In addition, it requires sophisticated maintenance (service contract costs U\$\$100,000/year) and calibration.	Costs of chemotherapeutic drugs vary from country to country. An entire course of treatment (consisting of 5 cycles of administration at weekly intervals) may cost between US\$200 and US\$1,000 per patient in many developing countries.

Features	Radical surgery	Radiotherapy		Chemotherapy
		Intracavitary (brachytherapy)	External beam (teletherapy)	
Hospital stay/ treatment duration	Inpatient stay of 10–14 days.	Low dose-rate brachytherapy usually requires a single hospital admission for 2–3 days. Requires operating room for the placement of intrauterine catheter and ovoids under general anesthesia. High dose-rate brachytherapy is done as an outpatient procedure, usually requiring no general anesthesia.	Performed as an outpatient procedure for patients living near the facility. Daily treatment takes about 10–15 minutes. About 20–25 treatments are delivered over 4–5 weeks (5–6 treatments per week).  Clear instructions on skin care are given to avoid the most common acute reaction, but some patients may require admission near the end of treatment for skin reactions.	Can be administered as an outpatient/ambulatory procedure, in weekly cycles over 5 weeks. Patients will require prophylaxis against severe vomiting.

# **Appendix 10.2. Commonly Used Analgesics for Cancer Pain Relief**

Category	Drug*
WHO Step 1 (Mild pain)	<ul> <li>Paracetamol</li> <li>Aspirin</li> <li>Ibuprofen</li> <li>Diclofenac</li> <li>Naproxen</li> <li>Piroxicam</li> </ul>
WHO Step 2 (Moderate pain)	<ul><li>Codeine</li><li>Dihydrocodeine</li><li>Oxycodone</li></ul>
WHO Step 3 (Severe pain)	<ul><li>Morphine (immediate release)</li><li>Morphine (sustained release)</li></ul>
Adjuvant drugs for:	
Neuropathic and musculoskeletal pain.	Amitryptiline
Malignant bone and nerve pain and to relieve spinal cord compression.	Dexametasone/Prednisone
Paroxysmal burning/electric shock-like neuropathic pain.	Carbamazepine/valproic acid
Pain due to bowel obstruction.	• Octreotide

 $<sup>^{\</sup>ast}$  For doses, refer to PATH and Engender Health 2003.

# Appendix 10.3. FIGO Staging Classification for Cervical Cancer

# Stage I

**Stage I** is carcinoma strictly confined to the cervix; extension to the uterine corpus should be disregarded. The diagnosis of both Stages IA1 and IA2 should be based on microscopic examination of removed tissue, preferably a cone, which must include the entire lesion.

**Stage IA:** Invasive cancer identified only microscopically. Invasion is limited to measured stromal invasion with a maximum depth of 5 mm and no wider than 7 mm.

**Stage IA1:** Measured invasion of the stroma no greater than 3 mm in depth and no wider than 7 mm diameter.

**Stage IA2:** Measured invasion of stroma greater than 3 mm but no greater than 5 mm in depth and no wider than 7 mm in diameter.

**Stage IB:** Clinical lesions confined to the cervix or preclinical lesions greater than Stage IA. All gross lesions, even with superficial invasion, are Stage IB cancers.

Stage IB1: Clinical lesions no greater than 4 cm in size.

**Stage IB2:** Clinical lesions greater than 4 cm in size.

# Stage II

**Stage II** is carcinoma that extends beyond the cervix, but does not extend to the pelvic wall. The carcinoma involves the vagina, but not as far as the lower third.

**Stage IIA:** No obvious parametrial involvement. Involvement of up to the upper two-thirds of the vagina.

**Stage IIB:** Obvious parametrial involvement, but not to the pelvic sidewall.

# Stage III

**Stage III** is carcinoma that has extended to the pelvic sidewall. On rectal examination, there is no cancer-free space between the tumor and the pelvic sidewall. The tumor involves the lower third of the vagina. All cases with hydronephrosis or a nonfunctioning kidney are Stage III cancers.

**Stage IIIA:** No extension to the pelvic sidewall, but involvement of the lower third of the vagina.

**Stage IIIB:** Extension to the pelvic sidewall or hydronephrosis or nonfunctioning kidney.

# Stage IV

Stage IV is carcinoma that has extended beyond the true pelvis or has clinically involved the mucosa of the bladder and/or rectum.

**Stage IVA:** Spread of the tumor into adjacent pelvic organs.

**Stage IVB:** Spread to distant organs.



# **Acronyms**

Alliance for Cervical Cancer Prevention **ASCUS** Atypical squamous cells of undetermined significance CHIP Cervical Health Implementation Project (South Africa) CHW Community health worker CIN Cervical intraepithelial neoplasia DNA Deoxyribonucleic acid DVI Direct visual inspection HIS Health information system HIV Human immunodeficiency virus **HPV** Human papillomavirus HSIL High-grade squamous intraepithelial lesion IARC International Agency for Research on Cancer LBC Liquid-based cytology **LEEP** Loop electrosurgical excision procedure **LLETZ** Large-loop excision of the transformation zone LSIL Low-grade squamous intraepithelial lesion MOH Ministry of Health NGO Nongovernmental organization **PAHO** Pan American Health Organization PATH Program for Appropriate Technology in Health **RTCOG** Royal Thai College of Obstetrics and Gynecology **SEER** Surveillance, Epidemiology, and End Results Program STI Sexually transmitted infection VIA Visual inspection with acetic acid VILI Visual inspection with Lugol's iodine WHO World Health Organization

# **Glossary**

- **Bethesda classification system:** A system of reporting cervical cytology results. It is aimed at producing more effective communication of cervical cytology results from the laboratory to clinicians. The system includes a descriptive diagnosis and an evaluation of specimen adequacy.
- **Biopsy:** Procedure of taking a sample of tissue for further evaluation in the pathology laboratory.
- **Cancer:** The generic term for a group of diseases that are characterized by the proliferation of abnormal cells.
- **Carcinoma** *in situ*: A precancerous stage of cancer involving the entire thickness of the squamous epithelium, but without penetration of the underlying membrane (basement membrane) that holds them within the tissue of origin.
- **Cervical cancer control:** Efforts to reduce the incidence of and mortality from cancer, as well as make improvement in the quality of life for women and their families.
- **Cervical Intraepithelial Neoplasia (CIN) classification system:** This system grades the severity of precanceous cervical lesions based on histology. According to this system, mild cervical dysplasia is classified as CIN I, moderate dysplasia as CIN II, and severe dysplasia and carcinoma *in situ* as CIN III.
- **Clinical supervisor:** A person who provides expert clinical oversight and clinical back-up to cervical cancer prevention services. He or she is not necessarily based full-time at the service delivery site and may only visit periodically.
- **Colposcopy:** Examination of the vagina and cervix using an instrument (colposcope) that magnifies the vaginal and cervical tissue.
- **Community:** The collection of factors and influences that affect people's lives, based on where they live, their culture, and the people with whom they interact.
- **Community health worker:** A person who works for the health care system and provides health care and education services outside the clinic setting by going to people's homes, places of work, or community gathering places.
- **Cold knife cone:** A surgical procedure involving the removal of a cone-shaped section of the cervix using a "cold knife" (scalpel). This procedure is done either under regional or general anesthesia. Since this procedure involves removing (excising) the tissue, the procedure is both diagnostic (providing tissue for histopathology) and therapeutic (removing the abnormal tissue).
- **Coverage:** Coverage refers to the extent of participation of eligible women in the screening program, and it is defined as the cumulative number of women in the target population who are screened in a given time period, divided by the total number of eligible women.

**Cryotherapy:** An outpatient treatment that uses extremely low temperatures to freeze and destroy abnormal tissue.

**Cytology:** The scientific study of cells, using a microscope.

**Direct visual inspection:** See "visual inspection with acetic acid"

**Dysplasia of the cervix:** A term used to describe precancerous abnormality of the cervical squamous epithelium.

**Health information system:** A system for collecting and sharing information required for patient management and for effective and efficient planning, managing, monitoring, and evaluation of programs.

**Health sector:** A grouping of health care services and programs, based on similar organizational or funding characteristics. The public sector is funded by governmental bodies or donor agencies, and the private sector is funded by client payment (either direct or through private insurance programs) and functions outside the governmental system.

**High-grade squamous intraepithelial lesion (HSIL):** A term used in the Bethesda classification system to describe cervical epithelial abnormalities that have a high likelihood of progressing to cervical cancer if not treated. Includes CIN II and CIN III.

**Histology:** The scientific study of tissue (obtained during biopsy) using a microscope.

**Human papillomavirus (HPV):** A virus that can be sexually transmitted and is often asymptomatic. High-risk types of HPV can slowly cause cellular changes on the cervix that result in cancer.

**HPV DNA test:** A screening test that detects whether oncogenic HPV types are present in a cervical sample (without distinguishing which type[s] are present).

**Hysterectomy:** Surgical removal of the uterus including the cervix.

**Incidence:** Incidence is the number of new cases arising in a given period in a specified population.

**Inreach services:** Use of facility staff to inform clients, visitors, and other staff in the health facility about cervical cancer prevention and the availability of services, and to refer eligible women to utilize these services.

**Integrated services:** An approach to service delivery in which a client can access more than one health service at the same facility, on the same day, and (sometimes) from the same provider.

**Invasive cervical cancer:** Abnormal cervical cells that break through the basement membrane, involve the surrounding tissue, and eventually spread to other organs.

**Linkages:** Communications between health facilities (or between departments in a tertiary-level facility) for planning and referral purposes, to promote continuity of care for clients.

- **Loop electrosurgical excision procedure (LEEP):** A procedure in which a thin wire electrode is used to remove the abnormal area on the cervix. (Also called large-loop excision of the transformation zone [LLETZ].) Excised tissue is available for histopathological examination.
- **Low-grade squamous intraepithelial lesion (LSIL):** A term used in the Bethesda classification system to describe mild cervical cellular abnormalities. It includes CIN I lesions.
- **Mass campaigns:** Usually an occasional health care "event" that lasts a short period of time and systematically provides health care services to large numbers of people in geographic areas where static services are unavailable or inaccessible.
- **Master trainer:** Trainer who has completed all phases of the training pathway and is therefore qualified to conduct courses in clinical skills, conduct courses to prepare new trainers, and independently develop training curricula. A master trainer is considered to be an independent expert who can function without external technical assistance.
- **Mobile services:** (Also referred to as outreach clinical services.) This refers to a service delivery *team* that functions as a mobile unit, traveling with all necessary equipment and supplies to underserved areas.
- Nonintegrated services: See "vertical services."
- **On-site supervisor:** A person who oversees day-to-day administrative and clinical activities of a cervical cancer prevention program in a given service delivery or clinic setting. She or he does not necessarily have clinical skills or clinical responsibilities.
- **Opportunistic screening:** Refers to services provided to women upon request or to those who are already in a health facility while seeking other services, without any effort to reach any particular population.
- **Organized screening:** Refers to programs in which a target population has been identified and strategies are developed and implemented to attract and provide services to the specific population.
- **Outreach clinical services:** (Also referred to as mobile services.) An approach to service delivery in which health services are offered in a variety of facilities temporarily used for the purpose—e.g., schools and health centers—where the service provided is not one regularly offered there.
- **Palliative care:** The constellation of services aimed to improve the quality of life of patients with life-threatening illnesses through the prevention, early detection, and relief of distressing symptoms and psychosocial problems.
- **Papanicolaou's test:** (Also referred to as Pap smear, Pap test, cervial smear, or cervical cytology.) A screening test in which a smear of cervical cells is taken and then evaluated at a cytology laboratory to detect abnormal cells.

**Pathology:** The study of disease and its effect on body tissue.

**Precancer:** Cellular conditions that are precursors to cancer.

**Precursor lesions:** Abnormal cervical cells that are likely to lead to cancer if not treated. Sometimes referred to as dysplasia.

**Prevalence:** The prevalence of a disease is the total number of cases in a defined population at a specific point in time. It is usually expressed as a percentage of the population.

Primary health centers: The lowest level of service delivery within the public sector, which consists of health centers, health dispensaries, and health posts. The centers usually offer only outpatient services and often are staffed by one or more nurses, clinical officers, or auxiliary health care workers (e.g., auxiliary nurse-midwives, health assistants). Primary health centers might not have a medical doctor on staff. These facilities focus mostly on disease prevention and health promotion activities. (The range of services and staff can vary by country.)

**Referral systems:** Communication linkages between health care facilities, for the purpose of helping clients or patients find services that are not available at the referring site.

**Referral facility:** A health facility to which a client is sent for services.

**Referring facility:** A health facility that sends a client elsewhere for services.

**Rescreening:** Repeating the screening test periodically (e.g., every three or five years) for all women in the target age group.

**Satellite clinics:** An approach to service delivery in which regular weekly, biweekly, or monthly services are provided by mobile teams visiting existing health care facilities.

**Screening test:** Any of a number of clinical procedures that involve visual inspection or sampling cells to detect the presence of disease or disease precursors.

Secondary health centers: Midlevel public-sector health care services, typically including hospitals at the district and province or state levels. These facilities serve as referral centers for a number of primary care facilities and generally include both inpatient and outpatient services, with surgical and some laboratory facilities. District hospitals may have only general practitioners on staff; provincial and state hospitals will have specialists as well. (The range of services and staff can vary by country.)

**Sensitivity:** The proportion of individuals correctly identified by a test as having disease.

**Service provider:** A person who provides services such as counseling, screening, or treatment.

**Specificity:** The proportion of individuals correctly identified by a test as not having disease.

**Squamocolumnar junction:** The area at which the endocervical columnar cells meet ectocervical squamous cells on the cervix. This junction marks the inner extent of the transformation zone.

- **Squamous epithelium of the cervix:** This area consists of multiple layers of thin, flat, irregularly shaped cells that cover the outer cervix.
- **Stakeholders:** Individuals who have an interest, knowledge, influence, or decision-making authority in developing and implementing a cervical cancer prevention program. This group includes people who can benefit from services as well as those who provide them.
- **Static services:** An approach to service delivery in which services are offered on a regular basis at an established facility (e.g., a health center, clinic, or hospital).
- **Tertiary health centers:** The highest-level facility in the health care system (also referred to as central or regional hospitals). They provide the most specialized and comprehensive care available, typically with the full range of medicine, surgery, and laboratory services available as well as an on-site pharmacy. Tertiary hospitals serve as the referral center for the hospitals at the secondary level and may also be teaching hospitals.
- **Trainer:** A person who is qualified to conduct courses on skills for cervical cancer prevention and control.
- **Trainer of trainers:** A trainer who is qualified to conduct courses in clinical skills, as well as courses to prepare new trainers. This person may or may not be a master trainer.
- **Tracking:** The ability of the health care facility or system to find out whether a client has returned for follow-up services (e.g., for treatment or post-treatment follow-up) or has received services at a referral site (or elsewhere).
- **Transfer-of-learning coach:** A trainer who conducts post-training follow-up visits to ensure that individual service providers perform to standard. May or may not be a trainer of trainers or a master trainer.
- **Transformation zone (T-zone):** The area of the ectocervix (the external portion of the cervix and os) demarcated by the outermost cervical crypt openings. The T-zone extends to the squamocolumnar junction, which is usually near the entrance to the endocervical canal. Cervical cancer usually originates in the T-zone.
- **Vertical services:** An approach to service delivery in which providers and facilities are dedicated to only one health care service.
- **Visual inspection with acetic acid (VIA):** (Also referred to as direct visual inspection [DVI].) A visual test to identify precancerous cervical lesions, which appear white for a brief period of time after staining with acetic acid (vinegar).
- **Visual inspection with Lugol's iodine (VILI):** A visual test that involves staining the cervix with Lugol's iodine. Normal cells take up the iodine stain and appear a mahogany brown, whereas precancerous cervical lesions appear yellow.

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