Planning and Implementing Cervical Cancer Prevention and Control Programs

A MANUAL FOR MANAGERS

ACCP Alliance for Cervical Cancer Prevention

EngenderHealth

International Agency for Research on Cancer

JHPIEGO

Pan American Health Organization

PATH

Endorsing Agencies

World Health Organization

Geneva

AFRO

INCTR

International Network for Cancer Treatment and Research

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Alliance for Cervical Cancer Prevention

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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.

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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

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ENGENDERHEALTH
Improving Women's Health Worldwide

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.

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IARC

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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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 nonexistent 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.