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## Advocating for cervical cancer prevention

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**Abstract** Cervical cancer is a significant health problem among women in developing countries. Contributing to the cervical cancer health burden in many countries is a lack of understanding and political will to address the problem. Broad-based advocacy efforts that draw on research and program findings from developing-country settings are key to gaining program and policy support, as are cost-effectiveness analyses based on these findings. The Alliance for Cervical Cancer Prevention (ACCP) has undertaken advocacy efforts at the international, regional, national, and local levels to raise awareness and understanding of the problem (and workable solutions), galvanize funders and governments to take action, and engage local stakeholders in ensuring program success. ACCP experience demonstrates the role that evidence-based advocacy efforts play in the ultimate success of cervical cancer prevention programs, particularly when new screening and treatment approaches—and, ultimately, radically new approaches such as a human papillomavirus vaccine—are available.

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### 1. Introduction

Cervical cancer represents a unique public health need and opportunity. With a death toll of approx-

imately 237,500 women each year, cervical cancer is the primary cause of cancer deaths among women in many developing countries [1]. According to recent data, approximately 85% of the new cases of cervical cancer (estimated at 493,000 worldwide) and deaths from cervical cancer that occur each year affect women in developing countries [2]. Yet, unlike most other cancers, cervical cancer is readily

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preventable when effective programs are implemented to detect and treat its precursor lesions.

A key barrier to the implementation of effective cervical cancer prevention activities is the lack of understanding and political will to address the problem. The burden of disease from cervical cancer is under-appreciated in many countries, and there is a poor understanding of the principles of effective prevention, as well as of the growing evidence base from developing countries that supports new approaches to cervical cancer screening and treatment. Changing this situation requires broad-based advocacy to gain program and policy support for effective cervical cancer prevention interventions. Advocacy efforts are important at the international, regional, national, and local levels. International agencies must be convinced to focus on cervical cancer prevention as a key component of improving women's health worldwide; regional efforts must galvanize governments to action and provide appropriate assistance to national efforts; national policymakers must understand the principles of cervical cancer prevention and build or improve national programs, policies, and guidelines; and local stakeholders must ensure that women, providers, and decision-makers understand programs and that services meet individuals' and communities' needs.

## 2. Reaching out globally

A number of global health priorities compete for the attention of the handful of organizations that are best positioned to have worldwide impact on public health programs and policies. Organizations such as the World Health Organization (WHO), the United Nations Population Fund, the U.S. Agency for International Development, and the World Bank can strongly influence the breadth and depth with which a particular health issue or group of issues is globally addressed. All of these organizations recognize women's right to the highest attainable standard of health, as articulated by the International Covenant on Economic, Social, and Cultural Rights, and that the right to health includes four interrelated features—the availability, accessibility, acceptability, and quality of health services [3]. The sharp inequity in cervical cancer deaths among and within countries clearly is at odds with women's right to health and international agencies are increasingly exploring ways to increase women's access to appropriate and effective prevention services.

Considerable research conducted in recent years makes it possible to present a clear case that

supporting the prioritization of cervical cancer prevention as a global health issue can save women's lives. Studies of screening methods that are simpler alternatives to cytologic screening suggest that these methods can greatly improve women's access to effective services, even in the poorest regions of the world [4–10]. Advances in the understanding of the safety, effectiveness, and acceptability of simple outpatient procedures to treat precancerous lesions indicate that the approach is appropriate in even the most remote settings [11]. Cost-effectiveness analyses of screening methods that are alternatives to cytology suggest that offering screening to women in resource-poor areas can be a feasible and appropriate public health intervention strategy (see Box on cost modeling below) [12,13] and that even a once-in-a-lifetime screening offered to women between the ages of 35 and 40 years can reduce lifetime risk of cervical cancer by 25–36% Table 1 [14]. Forming strategic global partnerships and communicating these types of findings to key international health organizations—and to the growing number of large private donors engaged in global health—is essential to the success of global advocacy efforts.

The Alliance for Cervical Cancer Prevention (ACCP) took a two-stage approach to ensuring that global health organizations obtain the best and most timely information to help inform their prioritization of health issues. During the initial phase of ACCP work, as research projects were being designed and initiated, it was clear that general understanding of cervical cancer prevention issues was low and that there was a great need for materials that synthesized what was known to date about cervical cancer and prevention approaches. Interviews conducted early in the project indicated that key leaders and decision-makers in several countries desired brief, non-technical synopses of issues based on the most current research findings [15]. The ACCP responded to this need by developing an array of resources, including fact sheets, program-planning materials, and presentation materials designed to provide accessible, up-to-date information about effective prevention strategies. (All materials are available at [www.alliance-cxca.org](http://www.alliance-cxca.org)).

As ACCP research projects were implemented, study findings became available and the ACCP moved to the second stage of disseminating information to influential global health organizations: providing the cutting-edge findings on alternative prevention methods for low-resource settings. In addition to publishing findings in refereed journals [4–9,16] and making presentations at regional and international meetings, new ACCP publications,

## Box 1

## Supporting advocacy efforts with cost-modeling

A new generation of models that addresses new approaches to cervical cancer prevention and the impact of once-in-a-lifetime interventions has advanced knowledge about the likely cost-effectiveness of cervical cancer prevention programs in developing countries. The models incorporate epidemiological patterns from developing-country populations, where cancer incidence and mortality remain high and where women have not benefited from organized screening programs. They also incorporate the effects of HIV and AIDS on program impact.

Recent modeling findings suggesting that new approaches to screening and treatment for precancerous lesion can be cost-effective alternatives to reaching women and preventing deaths in developing countries can be very powerful. For example, Goldie et al. [12] estimated the clinical benefits and cost-effectiveness of cytology, visual inspection with acetic acid (VIA), and human papillomavirus (HPV) DNA testing in South Africa. The model suggested that, for South African women, a single lifetime screening with VIA (one clinic visit) or HPV testing (two clinic visits), combined with immediate treatment for test-positive women, would reduce the incidence of cervical cancer by 26–32% and cost less than US\$50 per year of life saved (Table 1). Other model-based analyses have produced similar rankings of cost-effectiveness for different approaches [13].

A later analysis by Goldie and ACCP researchers [14] that drew on data from Kenya, Peru, Thailand, South Africa, and India confirmed this finding, estimating that programs based on a single lifetime screening with VIA or HPV testing (and follow up with cryotherapy for eligible women with positive results) and targeting women between 35 and 40 years of age would reduce the lifetime risk of cervical cancer between 25% and 35%. Although costs varied among countries, the study found that a single-lifetime screening strategy in each would be “very cost-effective”—that is the cost per year of life saved would be less than the per capita gross domestic product in each country. Cost-effectiveness was most influenced by strategy-specific loss-to-follow-up rates, age at screening, and the direct medical and programmatic costs associated with each screening approach. HIV prevalence had a negligible impact on cost-effectiveness of various single lifetime screening approaches in this analysis.

Descriptions of the results of these modeling exercises are a valuable advocacy tool at the international, regional, and national levels. Many policymakers view cervical cancer as an extraordinarily difficult and expensive health challenge and focus instead on health problems that seem more urgent or easily addressed. Modeling that demonstrates the cost-effectiveness and impact of new approaches can help to overcome these biases.

such as a series of issue papers, were developed to communicate new research and program findings and a website was created to make ACCP

progress, findings, materials, and tools accessible to a broad audience. To ensure that ACCP publications are meeting the needs of audiences and being used as intended, they have been evaluated through two reader surveys reaching individuals in 44 countries and through key-informant interviews in Kenya, Peru, El Salvador, and India. The majority of the more than 100 survey and interview participants—mostly health care providers and researchers—reported that the ACCP publications are very relevant to their work and provided them with new information about cervical cancer prevention.

Forming strategic partnerships with influential organizations also has helped the ACCP advocate effectively for increased recognition of cervical cancer as a global health problem. For example, collaboration between WHO, with its broad reach and global credibility, and the ACCP, with its

**Table 1** Cost-effectiveness of once-in-a-lifetime (at age 35 years) screening strategies

Screening strategies	Reduction in cervical cancer incidence, %	Cost-effectiveness ratio (\$/year of life saved)
VIA and treatment (single visit)	26	Cost saving
HPV testing and treatment (single visit)	32	14
Two-visit cytology	19	81
Three-visit cytology	17	147

Note: HPV, human papillomavirus; VIA, visual inspection with acetic acid. Based on mathematical models using data from South Africa (Goldie et al. [12]).

several large research and demonstration projects and its strong organizational partners, leverages the strengths of both groups. Gaining the formal approval of WHO, the International Network for Cancer Treatment and Research, and other organizations on ACCP documents, such as a manual for managers [17], gives these documents greater weight and legitimacy in the eyes of policymakers in many countries. Likewise, ACCP is providing input and assistance to WHO in developing practice guidelines for cervical cancer prevention. Coauthoring vital documents, coordinating participation in global and regional meetings, and working together to establish a broad strategy for addressing cervical cancer have been the hallmarks of the ACCP's partnerships with global health organizations.

### 3. Reaching out regionally

Another important strategy for raising awareness about cervical cancer prevention is through regional advocacy—working with groups of countries that share geographic, economic, and cultural features. Regions, however, can have high internal diversity. Therefore, the choice of a regional perspective for advocacy has to be flexible enough to consider subregions or particular groups of countries that are closely identified with each other.

Regional advocacy efforts need to engage a range of stakeholders who can influence decision-making in cervical cancer prevention. Ministries of health and nongovernmental organizations (NGOs) are key, as are international organizations that provide guidance on or funding for health issues. For example, a November 2000 regional meeting organized by the Royal Thai College of Obstetrics & Gynaecology and Thai Gynaecologic Oncology Society brought representatives from 20 countries together for a symposium on cervical cancer problems in Southeast Asia. The symposium focused on the epidemiological, medical, and public health aspects of cervical cancer management. Meeting participants concluded that cervical cancer is a major public health problem in the region and that appropriate use of single-visit approaches (visual inspection with acetic acid [VIA] followed immediately by cryotherapy was the primary approach discussed) would be acceptable and feasible in most countries of the region. The symposium also enhanced cooperation among gynecologic oncologists in the Southeast Asia region, who play an important role in launching effective cervical cancer prevention services in their countries.

Another regional initiative was a March 2004 meeting sponsored by the Open Society Institute in Albania, which brought together representatives from 12 countries in eastern and central Europe and the Newly Independent States. Meeting participants had implemented cervical cancer prevention activities through an ACCP small grants program and (with a ministry of health counterpart from their countries) shared their experiences and developed technical and policy recommendations related to cervical cancer prevention for the region.

The information needs of regional audiences vary according to their role in decision-making. Key stakeholders might need direct, updated technical information to help in developing a proposal or allotting funds for a cervical cancer prevention program, but they also may need human-interest stories to advocate at the political level. Information packages that are tailored for specific audiences and that contain a range of different materials, such as technical dossiers, fact sheets, women's stories, presentations, and short videos, meet a wide range of needs.

#### 3.1. Latin American and Caribbean region

In the Latin American and Caribbean region, four subregions are defined by sociopolitical bodies: the Caribbean, Central American, Andean, and Southern Cone subregions. The Pan American Health Organization (PAHO)—a member of ACCP—carried out advocacy efforts in these subregions by holding workshops with representatives from ministries of health, NGOs, medical and professional associations, and universities. The workshops were implemented in collaboration with the International Union Against Cancer and the PAHO/WHO country-based representation offices.

The subregional workshops helped build alliances between countries and stakeholders and provide a forum for the exchange of technical information among countries that have been implementing cytology-based screening programs for several years. This subregional process aided advocacy efforts by:

- encouraging Latin American and Caribbean countries to give priority and allocate resources to cervical cancer prevention programs;
- providing information about the technical and managerial aspects of successful cervical cancer prevention programs;
- creating new working relationships and partnerships across disciplines within countries and between neighboring countries; and

- stimulating countries to undertake critical needs assessments and strategic planning processes to improve their current programs.

Subsequent to the subregional workshops, more than 10 countries in the region have critically assessed their programs with assistance from PAHO/WHO, devised strategic program plans, and received seed funding to implement new strategies for cervical cancer prevention. Through meetings with ministers of health, joint planning and technical cooperation agendas have been established; for instance, a meeting of the Caribbean Caucus of Ministers of Health resulted in development of a strategic plan for a subregional approach for screening and treatment, which currently is being implemented.

#### 4. Reaching out nationally

At the national level, clear support from health leaders, combined with supportive policy decisions, appropriate regulations for medical services, and “buy-in” from the medical and educational infrastructure, greatly affects the success of cervical cancer prevention programs. The ACCP has worked in more than 20 countries worldwide, with efforts to strengthen (or initiate) cervical cancer prevention programs, often beginning with research or demonstration projects. The success of these programs often has hinged on engaging decision-makers and stakeholders early and repeatedly to ensure that supportive policies and regulations are developed to support program expansion and that protocols reflect the health realities and policy environment into which findings will be translated. By working with national bodies to explore how cervical cancer prevention services can be integrated with existing services wherever possible, the ACCP has avoided the creation of vertical programs that are difficult to sustain without significant external funding. Examples from Thailand and India illustrate the role and importance of advocacy at the national level as part of larger efforts to strengthen cervical cancer prevention programs.

##### 4.1. Thailand

Although a Pap smear-based cervical cancer prevention program has been in place for 40 years, annual screening coverage in Thailand remains low. One estimate suggests that fewer than 10% of eligible women have been screened [18]. Reasons for low coverage include insufficient numbers of

cytotechnicians and pathologists to process smears and address follow-up needs. This personnel shortage can result in long waits for results, loss to follow-up of women in need of treatment, inconsistent quality control, and reduced screening accuracy. Low rates of treatment coverage and screening test inaccuracy limit the potential for measurable reduction in morbidity and mortality.

In 2000, a team of Thai professionals joined with JHPIEGO, a partner in the ACCP, to test a single-visit prevention approach in one rural province as an alternative to the traditional multiple-step strategy. This approach linked testing with the offer of immediate treatment of suspect precancerous lesions or referral by trained nurses, using VIA as the test and cryotherapy as the treatment option [5].

To effectively implement the demonstration project, policies and regulations had to be addressed and modified so that trained nurses could treat eligible women with cryotherapy. It also was necessary to gain permission to treat VIA test-positive women without further confirmatory testing by physicians. The long-term policy objective was the inclusion of a VIA-based single-visit approach as an option to achieve coverage targets and morbidity and mortality reduction goals.

To achieve these advocacy objectives, a local technical advisory board was formed, periodic small group meetings with stakeholders from the Ministry of Public Health and medical professional organizations were held, and project results were presented at national, regional, and international meetings. All served to inform attendees of project progress, update people about the latest evidence (local or international), share lessons learned, and obtain feedback about the types of evidence most helpful in guiding policy and practice decisions. Additionally, publication of findings in journals respected by the medical community and media exposure served to raise the profile of the project and to provide a forum for public reaction to project objectives and findings. Finally, in-country project team members served as champions of the alternative approach in a variety of settings.

These national advocacy efforts have helped to garner support and guide policy decisions that have a significant effect on program impact. Health program decision-making and financial control is decentralized in Thailand and the Permanent Secretary of the Ministry of Public Health has announced that provinces can now choose whether to use the traditional cytology-based multiple-visit approach or the VIA-based single-visit approach to meet screening coverage targets. In March 2004, the Permanent Secretary convened all of the

country's provincial health officers in Nong Khai Province to showcase its single-visit approach-based cervical cancer prevention program. This attracted national press coverage and generated broader interest in use of this approach as an alternative to cytology-based programs in areas where the latter are not functioning effectively.

The ACCP's cervical cancer screening work is gradually making its mark on health care information and services in Thailand. The Nursing Council in Thailand has announced that it will include VIA testing and cryotherapy treatment skills in the preservice curriculum for nurses and, similarly, in January 2004, a single-visit approach was incorporated into the residency training program of the Department of Obstetrics and Gynecology at Chulalongkorn University. Cervical cancer prevention activities, including VIA and Pap smear testing, have also been included as part of the prevention and promotion budget of the government's new 30-baht per person health plan. In Roi Et Province, where the project piloted the alternative approach, the provision of VIA testing is now integrated into routine health center-level performance assessments. To date, nine other provinces also have elected to use a VIA-based single-visit approach to achieve cervical cancer screening coverage targets.

#### 4.2. India

Although the National Cancer Control Program in India was initiated in the mid-1970s, no organized screening programs for cervical cancer have been implemented in any Indian states and financial allocations for cancer control activities have been very limited [19]. National consultations on cervical cancer control agree that traditional cytology-based screening programs currently are not feasible in India in light of technical, financial, and personnel constraints [9].

In this context, the International Agency for Research in Cancer (IARC), a partner in the ACCP, is working with several Indian agencies to investigate alternative screening and treatment approaches in different parts of the country. This effort is supported at many levels, including by a 2001 national workshop on alternative strategies for control of cervical cancer. The workshop recommended assessment of the inclusion of visual inspection techniques as part of a cervical cancer prevention strategy in districts covered by the Modified District Cancer Control Program, a national program aimed at providing services for treatment, prevention, and early detection of cancer in rural communities [10]. Strategies used to achieve advoca-

cacy objectives in these projects included involving major international and national research institutions in protocol design and review, keeping stakeholders informed about project progress, disseminating preliminary results to illustrate that reasonable coverage could be achieved through an alternative screening project, and integrating cervical cancer prevention with efforts aimed at preventing/controlling other types of cancer.

The largest of the ACCP's Indian studies is a four-arm cluster-randomized, controlled intervention evaluating the comparative efficacy and cost-effectiveness of once-in-a-lifetime VIA (provided by nurses), conventional cytology, and HPV testing in detecting cervical neoplasia and in reducing the incidence of and mortality from cervical cancer in Osmanabad District, Maharashtra, India[9]. This study is a collaborative project involving the Nargis Dutt Memorial Cancer Hospital in Barshi, the Tata Memorial Centre in Mumbai, and the IARC.

Partnership with the Tata Memorial Centre (India's premier cancer center, which has been working on cervical cancer prevention activities for the last 20 years and has implemented the first rural cancer registry) created a strong collaboration between project staff and Ministry of Health officials and fostered discussion related to the replication of the project at a programmatic scale. Representatives of the Department of Atomic Energy and the Ministry of Health were invited to observe progress in the project. Each of these visits was used to discuss the importance of cervical cancer prevention, the different approaches to be used in the Indian context, and the components of the service-delivery strategy that could be replicated at a program scale. A second randomized, controlled study in the Dindigul District of Tamil Nadu that measured the effectiveness of once-in-a-lifetime VIA-based screening also has helped to demonstrate to policymakers the acceptability and feasibility of alternative approaches to cervical cancer prevention [16].

The combination of these Indian studies and an inclusive advocacy approach is making a difference. In August 2003, the Tata Memorial Centre was awarded 44 million rupees (approximately US\$1 million) by the Department of Atomic Energy, Government of India, to implement cancer control activities in two additional districts of Maharashtra State (Sindhudurg and Rathapuri) through existing primary health care centers. The Ministry of Health will indirectly fund the project by augmenting infrastructure for cancer screening and treatment equivalent to 30 million rupees (approximately US\$650,000). Cervical cancer prevention (based on VIA and visual screening with Lugol's iodine)

will make up a major part of the cancer control project in these two new districts, which will build on the experience of the Barshi project.

## 5. Reaching out locally

Local advocacy efforts can encompass a range of activities, such as lobbying government authorities and decision-makers for local policy changes, encouraging delivery of services at local health facilities, collaborating with women's groups to promote screening, and conducting outreach to encourage women to be screened. (For a related discussion, see Agurto et al. [20] in this supplement). Regardless of the approach, local advocacy is necessary in making the transition from scientific investigations to public health practice.

Many elements influence the success of cervical cancer screening and treatment at the local level. Women often are uninformed about screening and its importance and, consequently, there is little consumer demand or political imperative to initiate or enhance screening programs. Furthermore, competing health issues—most notably HIV/AIDS in sub-Saharan Africa—have commanded attention and resources, not only globally and regionally but also locally. Governments, private entities, and NGOs can influence resource allocation and policy decisions that restrict cervical cancer prevention activities. Involving these groups in project development from the outset to inform the process enhances the likelihood of sustainability and promotes local ownership. ACCP partners recognize that to have a significant impact on policy, it is crucial to actively advocate for the cause in the communities where ACCP projects are based.

The ACCP experience emphasizes the importance of directing advocacy efforts toward local audiences that can influence public health. ACCP projects in Peru and South Africa have reached out to community health and advisory groups, church groups, political groups, and existing health services and providers (including traditional healers). By engaging with community groups, ACCP partners learned about the barriers preventing women from undergoing screening and were better equipped to develop culturally appropriate strategies to overcome those barriers.

For example, collaboration with a range of stakeholders in the San Martín region of Peru has helped ensure that health promotion strategies provide comprehensive, culturally appropriate information and support to women who are eligible for cervical cancer prevention services. Community health promotion teams were key to

this process and included staff from the local health center, community leaders, and representatives from the San Martín Ministry of Health. Promotional activities have been carefully aligned with service availability to ensure that women who learn about the services have ready access to them [21].

Much of local advocacy relates to achieving a common understanding among stakeholders of the problem of cervical cancer and how to best address its prevention. Even when great strides toward consensus are made, government instability and staffing and economic changes can result in shifts in priorities and financial allocation. Continuous advocacy, even once agreement seems to have been reached, is essential.

### 5.1. South Africa

The Khayelitsha Cervical Cancer Screening Project is a partnership between University of Cape Town, Columbia University in New York, and EngenderHealth, an ACCP partner. During planning and implementation of the project, numerous steps were undertaken to ensure local support for and commitment to research and service-delivery activities and to establish and maintain an open dialogue with a variety of community organizations and representatives.

Project staff approached and worked with several local health authorities and community-based organizations to carry the project forward, including the local community health forum, composed of elected representatives from the state health sector in Khayelitsha and local politicians elected by the community; the traditional healer association; community health service organizations (day hospitals); local NGOs; and the Department of Health in South Africa. The project proposal was presented to these parties for feedback, initiating interaction that continued throughout the project. Project staff attended periodic meetings to provide updates on activities and results to date, to report on any issues that arose, and to receive input from stakeholders. These actions resulted in greater transparency, consensus, and collaboration as the project moved forward.

Annual health festivals exemplified how the project worked with other health structures, local authorities, and respected community members (e.g., church leaders, traditional healers, and street committee leaders) to generate support and momentum for improving women's health. These celebrations of women and women's health were held in community halls where produce was sold, entertainment was provided, and important

health messages about HIV, family planning, child immunization, and cervical cancer prevention were conveyed.

Other community outreach activities by project staff that have provided an invaluable link between the project, the community of Khayelitsha, and the larger health sector include:

- participation in local and national call-in radio programs;
- delivery of lectures to nurses and doctors employed by the state and working in primary health clinics in Khayelitsha that address a wide range of women's health topics. Each lecture incorporated cervical cancer screening to reiterate its importance;
- participation in meetings with local metropolitan health authorities;
- participation on the task team for the implementation of national cervical cancer guidelines; and
- meeting with local NGOs working in health promotion.

## 6. Conclusions

Cervical cancer is a significant health problem among women in developing countries. Contributing to the lack of effective cervical cancer prevention programs in many countries is the lack of understanding and political will to address the problem. Broad-based advocacy efforts based on research and program findings from developing-country settings, combined with cost-effectiveness analyses based on these findings, are key to gaining program and policy support for prevention programs. As this article has described, these efforts—at the international, regional, national, and local levels—can raise awareness and understanding of the problem (and workable solutions), galvanize funders and governments to take action, and engage local stakeholders in ensuring program success. Strategic, evidence-based advocacy efforts will continue to be important in the coming decades, as the number of older, at-risk women grows worldwide and new cervical cancer prevention interventions—including HPV vaccines—become available.

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