A Strategic Assessment of Cervical Cancer Prevention and Treatment Services in 3 Districts of Uttar Pradesh, India

Rasha Dabash[1§], Jyoti Vajpayee[2], Martha Jacob[3], Ilana Dzuba[3] , Nisha Lal[2], Jan Bradley[3], L.B. Prasad[4]

[1] Consultant, Santa Monica, California, USA
[2] EngenderHealth, New Delhi, India
[3] EngenderHealth, New York, USA
[4] Director General of Family Welfare, Uttar Pradesh

[§]Corresponding author

Email addresses:
RD: rdabash@msn.com
JV: jvajpayee@engenderhealth.org
MJ: kmj131@yahoo.com
ID: ilanadzuba@hotmail.com
NL: nlal17@reddifmail.com
JB: jbradley@engenderhealth.org
LBP: jnsrivastava@hotmail.com

Abstract

Background

Despite being a preventable disease, annually cervical cancer claims the lives of almost half a million women worldwide each year. India bears one-fifth of the global burden of the disease, with approximately 130,000 new cases a year. In an effort to assess the need and potential for improving the quality of cervical cancer prevention and treatment services in Uttar Pradesh, a strategic assessment was conducted in three of the state's districts: Agra, Lucknow, and Saharanpur.

Methods

Using an adaptation of stage one of the World Health Organization's *Strategic Approach to Improving Reproductive Health Policies and Programmes*, an assessment of the quality of cervical cancer services was carried out by a multidisciplinary team of stakeholders. The assessment included a review of available literature, observations of services, collection of statistics and qualitative research (in-depth interviews and focus group discussions) to assess the perspectives of providers, policy influentials, community members and clients.

Results

Findings suggest tremendous need and potential for improvements in the quality of cervical cancer prevention and treatment services in all sectors. Despite the limited availability and poor organization of services, the capacity existed to improve quality, including access. There were gaps in provider knowledge and practices, potentially attributable to limited provider training and professional development opportunities. In

the absence of a state policy on cervical cancer, screening of asymptomatic women was practically absent, except in the military sector. Laboratory based Pap testing was often erroneously used to help diagnose women with symptoms of reproductive tract infections. Access to appropriate treatment of precancer was limited and often inappropriately managed by hysterectomy in many urban centers. Cancer treatment facilities were well equipped but similarly inaccessible to women in need. Finally, policy influentials, community members and clients were mostly unaware about cervical cancer and its preventable nature, although with information, expressed a strong interest in having services available to women in their communities.

Conclusions

To address gaps in services and existing unmet need, state policies and integrated interventions have the potential to improve the quality of services and prevent cervical cancer in Uttar Pradesh.

Background

Cancer of the cervix is preventable, yet approximately 493,100 new cases of the disease and 273,449 deaths occur each year among women worldwide.[1] While evidence of effective screening programs can be seen throughout the developed world, the burden and impact of the disease remains high in developing countries, where 85% of disease related deaths occur.

India, which accounts for one sixth of the world's population, also bears one fifth of the world's burden of cervical cancer.[2] There are approximately 130,000 new cases of cervical cancer cases a year in India[1] and the disease is reported to be responsible for almost 20 percent of all female deaths there. India's cervical cancer age-standardized incidence rate (30.7 per 100,000) and age-standardized mortality rate (17.4 per 100,000) are the highest in South Central Asia.[1] Data are limited, although some from Mumbai suggest that there may have been a slight decline in cervical cancer incidence in recent years: however, absolute incidence is still very high, especially in rural areas, and the number of cases grows due to high population growth.[2] Also, there is evidence that India is on the verge of a large HIV epidemic [3]. The Indian National AIDS Control Organization estimates that the number of people living with HIV was approximately 5.1 million, 38% of whom were women[4], a figure expected to rise to 49.5 million by the year 2015.[5] With a strong association between HIV and HPV infections, and evidence of more rapid progression of HPV infections to cervical neoplasia in HIV infected women[6] this is a cause for concern. [7]

Global evidence demonstrates that the key to averting cervical cancer morbidity and mortality is early detection through routine screening of women coupled with timely treatment of cervical precancer lesions. Cervical cytology often referred to as the *Pap smear* is perhaps the most well known of available screening methods. However, newer screening techniques such as visual inspection methods and HPV-DNA testing have also demonstrated tremendous potential for early detection in many settings, including several developing countries where the technologies are being assessed by the Alliance for Cervical Cancer Prevention (ACCP) among others. As critical as detection is, the need for women with positive results to receive timely treatment for dysplasia (which can be done using low morbidity outpatient procedures such as cryotherapy or Loop Electrosurgical Excision Procedure (LEEP)), is paramount.

With early detection and timely treatment in mind, the World Health Organization recommends that minimally, resource poor nations should screen all women at least once in a lifetime, and focus on women between the ages of 35-40 when likely-to-progress, high- grade, but treatable, lesions can be found.[8] There is some debate about whether this age limit is too high, [9] especially in countries with high HIV incidence, although recent data from South Africa study of 20,000 women showed the mean age of cancer to be 51.6 years.[10] In India in 2003, 46.6% of HIV cases in women occured in the 15-29 age group.[4] More research is needed to understand how this will impact cervical cancer rates. In practice, India, like many other developing countries, does not have a national vertical or integrated program for screening asymptomatic women and treatment of precancer, nor is it a component of the Indian HIV program. Some Indian states offer some ad hoc

cervical cancer prevention and treatment services; however, the quality, including access to such services and programs, varies greatly by region partly due to the absence of related policies and standards for providing those services.

In an effort to assess the need and potential for improving the quality of cervical cancer prevention and treatment efforts in Uttar Pradesh, India's most populous state, staff of the Directorate General of Family Welfare in the Uttar Pradesh Ministry of Health and Family Welfare collaborated with EngenderHealth, an international reproductive health organization and member of the Alliance for Cervical Cancer Prevention, to conduct a strategic assessment of services in three of the state's districts: Agra, Lucknow, and Saharanpur.

This article summarizes the process and findings of the assessment and presents strategies and recommendations proposed by stakeholders to address gaps in the quality of cervical cancer services in Uttar Pradesh.

Methods

The assessment was designed to evaluate the quality and accessibility of cervical cancer services and was conducted between March 2004 and August 2004. The assessment used an adaptation of the first stage of the Strategic Approach to Improving Reproductive Health Policies and Programmes[11], an approach first adapted for use in assessing the quality of cervical cancer services in Bolivia in 2002[12]. Guiding this strategic assessment process were these three strategic questions:

1. *Is it necessary to introduce policies and interventions for screening, diagnosis and treatment of precancerous cervical lesions in Uttar Pradesh?*
2. *Is it necessary to improve the quality of information management systems and cancer registry for the prevention, diagnosis, and treatment of cervical cancer in Uttar Pradesh?*
3. *Is it necessary to improve services for the treatment of cervical cancer in Uttar Pradesh?*

In addition to a review of available literature, field data were collected during three consecutive weeks by a 30 person multi-disciplinary team of stakeholders that included representatives from the Uttar Pradesh Directorate General of Family Welfare, policy-makers, administrators, statisticians, social scientists, researchers, gynecologists, pathologists, public health personnel, cytotechnicians, NGO representatives and community advocates. Data were also drawn from observations of health facilities and services in the public, military and private sectors (Table 1). In-depth interviews and focus group discussions were conducted with individuals (n=1197) from key respondent groups, including clients, community members, provider, and policy-makers (Table 2). Observations were conducted in sites where cervical cancer services were offered or could potentially be offered as a part of reproductive health services. Using a combination of purposive and snowball sampling, participants and health facilities were identified across 18 communities, including urban, peri-urban, and rural communities. A 10-member expert Technical Advisory Group guided technical aspects of this assessment

and facilitated strategic planning for positioning findings and recommendations within the broader scope of reproductive health and rights.

Based on the multi-disciplinary team's joint analysis of data from the three districts, responses to the strategic questions were formulated and presented to a wider stakeholder audience at a meeting in Lucknow. Findings were framed according to their relationship to recognized elements of quality cervical cancer prevention and treatment programs and services[13,14]; 1) availability, organization, and capacity of services; 2) access to services; 3) community knowledge; 4) knowledge and practices of health service providers; 5) training and professional development of providers; 6) quality improvement, including supervision and monitoring; and 7) information systems and cancer registries.

Results

Due to inadequate epidemiological data and literature, the magnitude of cervical cancer morbidity and mortality in Uttar Pradesh was not determinable but suspected to be high. Population-based incidence and mortality data from surveillance sites outside of Uttar Pradesh suggest that cervical cancer is the primary or secondary cause of female related cancer deaths in several urban centers, and may even be higher in rural districts. [15]

First, no state policy or guidelines on cervical cancer prevention exist in Uttar Pradesh. The strategic assessment identified and examined some isolated cervical cancer prevention and treatment services; however, well-coordinated prevention and stage-appropriate treatment services, particularly in the public sector and outside large urban centers, were absent. Evaluation of the quality of the limited available services in the

public, private and military health sectors revealed significant variability in their quality, including cost and accessibility. Simultaneously, it suggested tremendous potential for improving and expanding efforts to reduce disease burden

Availability, Organization, and Capacity of Services

Screening for Cervical Precancer and Cancer

There was no routine screening of asymptomatic women being implemented in health facilities within the assessment districts, with the exception of a few *private* providers and military hospitals, which reported routinely screening asymptomatic women over age 35 every three years using Pap smears. In the public sector, Pap smears were mostly limited to the tertiary care level on an outpatient basis, and mostly only offered to women with symptoms of reproductive tract infections or advanced cervical cancer symptoms upon clinical examination. In the public and private sector, women usually first received a pelvic examination by their gynecologists and were then either referred to the hospital's pathology department or to a private pathology laboratory for their Pap smear.

Cytopathology Services

An assessment of laboratory facilities, including public pathology labs in tertiary institutions and private labs collecting and/or processing Pap smears, revealed a great deal of variability in the procedures used for sample collection, processing, reading and reporting of Pap smears. Few of the labs visited were accredited for cytopathology, as required by the Indian Association of Cytopathology (IAC). Many, particularly private labs also lacked familiarity with the Indian Association of Cytopathology norms for

cytopathology services. Most sites were processing a minimal volume of Pap smears but had the capacity to handle a significantly larger load if provided with additional resources, principally, trained staff and supplies.

Diagnosis and Treatment of Precancer

Equipment and services for diagnosis and treatment of precancerous lesions, including colposcopes and cryotherapy were readily available in military sector facilities and a few *private* facilities, yet rarely available or functioning in *public* tertiary sites. Some sites had cryotherapy equipment but were only using it to treat 'cervical erosion'; few staff at these sites knew that it could be used to treat cervical precancer. Thus, in the public sector and in many private facilities, invasive inpatient procedures such as hysterectomy were the first line of treatment and management of women with precancer, even for mild dysplasia.

Cervical Cancer Treatment, including Palliative Care

Due to lack of screening most women with cervical cancer were diagnosed in later, less treatable stages of the disease. Uttar Pradesh had 11 well-equipped cancer treatment facilities. However, radical surgery to treat early stages of cancer and external radiotherapy for later stages, while available to private and military sector clients, was inaccessible to public sector clients in two of the three districts. Frequently, women using public services had to travel to other districts in Uttar Pradesh or to New Delhi for cancer treatment services. More scarce was access to palliative care for women in terminal stages of cancer, including opioids for relief of extreme pain. Only one non-governmental

organization had recently started providing palliative care services in one of the assessment districts.

Factors impacting Access to Services

In addition to the limited geographic availability of highly centralized services (Table 3), there were several factors affecting women's access to cervical cancer prevention and treatment services. Where offered, the poorly coordinated and erratic frequency and organization of services in the public sector, which often depended on a single provider's presence, often translated into women having to make numerous visits. The poor organization of services also increased the likelihood of loss to follow-up.

The costs of services also varied considerably by site and sector (Table 4), but even in the public sector, consultation fees coupled with the often costly indirect costs of having to seek services (transportation, lost wages, long waits, etc.) were reported to negatively impact access. As one client interviewed said, *"the hospital is very far from my home. So it takes a very long time and costs about Rs. 80 in transportation."* For many, this equivalent of two days wages was often too costly.

Equally important, negative community and clients' perceptions of the quality of public sector services in particular sites were also reported to discourage clients from seeking care for non-ambulatory reasons and in the absence of troublesome symptoms. *"If I do not have any pain or any other symptoms, why should I go for examination?* asked one client interviewed. These discouraging factors were often compounded by the socio-

cultural notions challenging women's comfort with having a pelvic examination, especially by a male provider.

Issues of confidentiality and privacy were not just barriers to women getting screening but were a reality for women diagnosed with cervical cancer. As one woman undergoing radiotherapy said, "*The hardest part of this is that I have lost my dignity. What was once private, I now have to discuss with the doctor in front of my son."* Male relatives were often reported to play a key role in the negotiating and accessing services for women. Finally, given the limited financial means of many community members, the value of women's health and prevention were often reported as secondary to competing financial and social responsibilities. As one provider explained, "*for many of the patients, meeting daily needs is more crucial; preventive care and detecting cervical cancer is not the priority."*

Community Knowledge about Cervical Cancer

Information, Education and Communication (IEC) campaigns on breast, prostate and oral cancers had raised awareness in communities about the causes and prevention of these diseases. This was not the case for cervical cancer for which virtually no IEC materials or efforts promoted its preventable nature in the vast majority of communities and facilities visited. Where available, counseling in tertiary facilities for women getting Pap smears or treatment for cervical cancer was often inadequate and failed to address a client's right to complete and accurate information. As such, most community members who participated in the assessment reported familiarity with other forms of cancer, but rarely knew of cervical cancer. Only very few community members and clients who knew someone who

had been diagnosed with cervical cancer reported some familiarity with the disease, but also did not know that it was preventable.

Knowledge and Perceptions of Community Women

Few community members or asymptomatic clients had ever been screened for cervical cancer. Those that had ever had a Pap smear or were interviewed when they presented for this service at health facilities also did not know that the test could help in preventing cervical cancer. Similarly, women interviewed who were undergoing treatment for early and late stage cervical cancer were often unaware of their exact diagnosis or if aware, did not know the cause of the disease for which they were being treated.

"I only know cancer by name. It is a disease which cannot be treated. So a person dies. My grandmother had some genital cancer about 5-6 years back. She was treated, but ultimately she died. For many, including this female community member, cervical cancer was commonly equated with death. "*I am ashamed of this disease in this old age,"* said one woman interviewed who was undergoing radiotherapy for cervical cancer. Since many believed that cervical cancer was caused by poor hygiene, high parity, promiscuity, fibroids, and/or use of contraceptive pills or IUCD, many reported fearing that a cervical cancer diagnosis would bring a woman shame, blame and even abandonment by her husband and family. Given such stigma, most women interviewed who were suffering from cervical cancer had not been told about the nature of their disease, mostly at the request of family members. A few women believed that the cause of cervical cancer was the pelvic examinations; believing it was the cause of the disease based on the perception that it could activate or exacerbate dormant cancer cells.

Knowledge among Community Men

The perceptions of community men and male clients were similar to those of women. Male respondents were as likely as women to have misconceptions about the cause of cervical cancer. Some men reported discomfort discussing matters of reproductive health or sexuality with women; yet, most were willing to encourage their wives and female relatives to be screened upon learning of the potential benefit of screening. Possibly as a result of screening campaigns run by the military hospital, male clients interviewed in those facilities were aware that women above the age of 35 years should have regular examinations and undergo tests, but most were not sure why the tests were being performed or familiar with the preventable nature of cervical cancer.

Awareness among Community Leaders

Likewise, community leaders, while generally unaware of the cause and magnitude of cervical cancer, were particularly interested in learning how they could facilitate prevention and awareness, particularly IEC and screening campaigns. Many stressed the importance of access to these services, particularly at the community primary health level. As one community leader said: "*I will make Cancer Cervix on the priority list, I will be the part of the team to make the community aware about the disease. I will involve ANMs (midwives) to visit house to house so that they can talk to women one on one basis. But the program should come to our community."*

Provider Knowledge and Practices

Many providers had considerable knowledge about the link between cervical cancer and Human Papilloma Virus (HPV), yet gaps were commonly noted in provider understanding of the natural history of cervical cancer, its preventable nature, treatment of precancerous lesions, and stage-appropriate clinical management of cancer. Knowledge about cervical cancer was generally better at higher-level facilities and in the private and military sectors. Furthermore, physicians were generally more aware about cervical cancer issues than mid-level and paramedical staff. It was not uncommon that doctors interviewed were unaware of the long period in which precancerous conditions could be detected and treated; one reason perhaps why few were performing routine screening of asymptomatic women or inappropriately targeting younger women with Pap tests. Military sector providers were generally more versed in the importance of age-targeted interval screening and population coverage strategies to reduce cervical cancer morbidity and mortality.

While familiar with Pap smears, few providers had knowledge of alternative screening approaches to the Pap smear, such as HPV-testing and visual inspection methods (e.g. visual inspection with acetic acid (VIA) or visual inspection with Lugol's iodine (VILI)). Most gynecologists in public and private facilities reported competence in taking cervical samples for Pap smears but said that they generally referred clients to pathology labs for the pathologists, residents or female technicians to take the cervical sample. Some reported doing so for their own convenience while others believed that laboratory personnel were better suited to take smears. Observations and provider interviews

suggested that at least some of the cervical samples collected were of poor quality due to noted gaps in provider practices, such as using cotton swabs to collect samples or improperly collecting the cervical smear.

"*I treat dysplasia I and II with an antibiotic and antioxidant course for three months then repeat the Pap smear. If it progresses or remains the same, I advise hysterectomy."*

Similar to this public sector provider, most doctors interviewed did not differentiate between treating precancerous lesions and cancer, and frequently prescribed or performed hysterectomies to manage most forms of dysplasia. Mid-level and nursing staff rarely knew the difference between cervical precancer and cancer or about stage-appropriate treatments either. Additionally, few public sector providers had been trained or had access to colposcopes for cervical cancer diagnosis. Access to and knowledge of the value of simple and effective precancer treatments such as cryotherapy and LEEP were also limited among providers in the public sector, but considerably better among private and military sector providers and public sector oncologists and radiotherapists. Palliative care as a way of providing clinical and psychosocial support, including pain relief for those in the end stages of life, was generally poor among most providers.

Training and Professional Development of Health Providers

Discussion with providers and those responsible for training medical and nursing student in the assessment districts suggested that gaps in provider knowledge and failure to integrate cervical cancer prevention were mostly attributable to the limited access to relevant pre-service training and professional development opportunities. Few medical

teaching institutions were routinely training gynecology residents to perform Pap smears, colposcopy or cryotherapy. Those responsible for offering cancer treatment generally had formal postgraduate training in radiotherapy. Pathologists generally reported having received postgraduate training in reading cervical smears but had learned to take Pap smears on the job. Cervical cancer issues were not included in the theoretical or practical training of nurses. Staff at almost all laboratories visited complained of shortages of formally trained cytotechnicians. Most labs were instead relying on lab technicians that they had trained themselves to perform the function of cytotechnicians.

In addition to the gaps in formal medical and nursing training and education and the reliance of providers on self acquired on-the-job skills, there were few opportunities for continuing professional development in reproductive female oncology. The Federation of Obstetric and Gynecological Society of India (FOGSI) had recently published a review of screening methods and approaches, but only a handful of the gynecologists interviewed were even aware of this resource. Similarly, highly respected national organizations such as the Indian Medical Association and the Indian Association of Cytopathology, with the potential to reach a wide membership, were rarely cited as sources of information on cervical cancer issues by providers interviewed.

Quality Improvement and Quality Assurance

Functioning quality improvement systems, which include effective supervision and monitoring, are key aspects of any health program. Likewise, internal and external laboratory quality assurance systems essential to for quality improvement were also lacking in most laboratories. Most ad-hoc cervical cancer services were not based on any

official policy and were generally integrated into the services provided in several departments (gynecology, pathology, and oncology) without clear guidance and indicators of what constituted quality and how it should be monitored. Although some facilities initially reported that they had internal quality improvement systems, there was little evidence of these in most sites visited.

Information Systems and Cancer Registries

The purpose of cervical cancer information systems and registries is two fold. First, they contain data that can be used to track and follow-up clients with positive results or in need of referral. Second, they can quantify the magnitude of morbidity and mortality associated with the disease in any given setting. In Uttar Pradesh, neither information systems nor cancer registries existed. Even facility-based data, collected routinely by districts on infectious and communicable diseases precluded any indicators or data on cervical cancer. A pilot program was in development and planned for expansion by the state of Uttar Pradesh that would allow for standardized electronic data collection from primary to tertiary facilities, yet at the time of the assessment there were no plans to include indicators on cancer.

A few private and military sites doing Pap smears were found to be using high tech computerized systems to capture client data for tracking and billing, but more commonly non-standardized manual registries were used by sites. Since referrals and follow-up were generally presumed to be the patient's responsibility, few sites tracked those with positive Pap smear results for timely treatment and as many as 80% of women reportedly failed to

return for their results in some sites. Follow-up was rarely conducted to track clients with cervical precancer or cancer.

Discussion

Assessment findings suggest tremendous need and potential for the expansion of cervical cancer prevention and treatment services in the public and private sectors. To develop cost-effective strategies for improving quality and increasing access to prevention and treatment services that would reduce the burden of the disease, responses to the three strategic questions were considered by stakeholders:

Is it necessary to introduce policy and interventions for screening, diagnosis, and treatment of precancerous cervical lesions?

While there were some isolated services providing early detection and treatment of cervical precancer, staff were often managing services with little guidance. All primary care providers could benefit from a clearly articulated state policy and guidelines on cervical cancer prevention as a reproductive health right. Policies and efforts should be considered in light of multiple competing health priorities in Uttar Pradesh and should build on existing resources and services, provider and system capacities, and community perceptions. State-level policy should include an emphasis on pre-service medical education. Professional institutions may be key to reaching existing and future generations of providers with the knowledge and skills needed to deliver effective services. Our study found that as in many countries, many providers were unaware of the natural history of HPV infection and appropriate timing, and frequency of screening interventions. Orientation to international guidelines on target age groups, screening frequency and the need for increased coverage is urgently needed.

To address the tremendous lack of awareness and information among providers, clients and the community at large about cervical cancer, IEC materials about cervical cancer and its preventable nature should be developed and disseminated along with information for women over 35 years old on where and how to get screened. Simultaneously, interventions will be needed to meet generated demand by maximizing the capacity of existing technologies and resources in the urban and peri-urban areas with functional linkages to the primary community level. In particular, program planners could educate providers about the synergies between HIV and HPV, include cervical lesions in the list of opportunistic infections, and look at the possibility of providing screening services in the growing number of voluntary counseling and testing (VCT) centers, of which there are currently 70 in Uttar Pradesh.[4]

Is it necessary to improve the current information system and cancer registry for the prevention, diagnosis and treatment of cervical cancer?

Since testing women without the possibility of timely and efficient notification of results and linkages for treatment would be pointless, functional mechanisms for tracking women for follow-up care need to be introduced. As suggested by community leaders, NGOs and community groups should be engaged to play a key role in these aspects, provided attention is paid to confidentiality and client rights. Minimally, manual facility-based information and tracking systems are needed to ensure follow-up of clients with positive Pap smear results. Opportunities for collecting population-based data on coverage, morbidity and mortality should also be considered as interventions become

integrated into reproductive health services. The potential of linking with state-based and national information systems to collect these data should also be explored.

Is it necessary to improve the existing services for the treatment and management of cervical cancer?

Given the capacity of the 11 well-equipped cancer treatment centers in Uttar Pradesh and the need for centralized cancer treatment as a way to maintain the considerable competence and resources necessary for these services, it is suggested that stronger linkages and referral systems to these facilities are needed, particularly for women in districts with limited services. To offset the potential cost burden of transport and lodging for women and their families during treatment, community and NGO supported mechanisms should be established to provide women and their care-taker(s) with necessary support. Within these facilities and at the community level, emphasis should also be given to palliative care services, including the psychosocial support for women in terminal stages and their families and the provision of appropriate medications, including opiates for pain relief.

Conclusions

With wide availability of prophylactic and therapeutic HPV vaccines still in the future, and evidence that other primary prevention measures are not useful,[16] secondary prevention, in the form of screening and treatment of precancerous lesions, is the only way to reduce the incidence of cervical cancer at the present time. Findings of the strategic assessment suggest strong unmet need for policies and interventions to expand women's access to screening, diagnosis, and treatment of cervical precancer services as

well as stronger linkages with cancer treatment facilities for those diagnosed with cervical cancer. In his regard, India is not atypical of many low resource settings in the world, where programs are lacking or failing due to inadequate legislative and regulatory frameworks, poor quality services, outdated knowledge and uninformed consumers. As in other settings, political will and resources, need to be made available. However, even without large resources, it is possible to develop programs by assessing needs, re-assigning existing resources more wisely and creating synergies between different stakeholders. For example, it is useful to focus limited staff and laboratory resources on screening women in key older age groups, rather than on very young women. It might also be useful to create innovative new linkages with services that focus on older women, for example, hypertensive clinics, or those who manage clients with a high risk of HIV. Such efforts have the potential to improve the quality of, and access to cervical cancer services, and to save the lives of thousands of women who would otherwise needlessly suffer or die from this preventable disease in Uttar Pradesh and similar resource-limited regions around the world.

Competing interests

None of the authors of this manuscript has any financial or non-financial competing interests.

Authors' contributions

RD coordinated the research process, participated in all aspects of data collection and analysis and authored this manuscript.

JV coordinated the assessment in India with the Directorate General of Family Welfare, participated in the assessment process and provided feedback on this manuscript.

MJ provided clinical and research leadership during the assessment, participated in all aspects of the assessment and provided input on this manuscript.

ID provided programmatic and technical input to the assessment and input on this manuscript.

NL participated in the strategic assessment and provided input on this manuscript.

JB provided technical support to the planning of the assessment and technical input on the final report and this manuscript.

LBP facilitated the assessment coordinated process in Uttar Pradesh, served as a member of the technical advisory group and reviewed assessment findings and this manuscript.

Acknowledgements

The authors wish to acknowledge all the members of multi-disciplinary strategic assessment team and members of the expert technical advisory group for their hard work and dedication to this important process. They also wish to acknowledge the contributing professional and support staff from EngenderHealth in the US and in India and those from the office of the Director General for Family Welfare, Uttar Pradesh. The authors would like to express their deepest gratitude to the facilities, participants and respondents, particularly the women suffering from cervical cancer who graciously gave of their time

and thoughts in this assessment in the name of improving services for their communities. Finally, we would also like to thank the Bill & Melinda Gates Foundation for generous funding to the Alliance for Cervical Cancer Prevention (ACCP) of which EngenderHealth is a member and grant recipient.

Tables

Table 1: Number of Sites Visited in all 3 Districts by Sector.	
Public Sector	
▪ Specialty Cancer Centers	3
▪ Tertiary Hospitals	2
▪ Second Referral Sites (District Hospital)	7
▪ First Referral Sites (Community and primary health centers)	15
▪ Maternal and Child Health Units	3
▪ Laboratories	5
Private Sector	
▪ Private Doctors, Clinics, Nursing Homes, Hospitals	21
▪ Private Labs	19
▪ Community, Faith-based, and Non-Governmental Organizations	10
▪ Other	6
Military Sector	
Military Hospitals	3
TOTAL SITES	**94**

Table 2 – Sampling by Respondent Category (N =1197 respondents)	
REPRODUCTIVE HEALTH SERVICES CLIENTS	
Female RH Clients (FGD and IDI)	176
Male RH Clients (FGD and IDI)	35
Clients with Cervical Cancer (IDI)	9
COMMUNITY MEMBERS	
Women (FGD)	319
Men (FGD)	58
Community leaders/Influentials (IDI and FGD)	74
POLICY INFLUENTIALS	
Policymakers, health authorities, health program directors (IDI)	71
PROVIDERS (Interviews and Focus Group Discussions)	
Obstetricians/Gynecologists (IDI)	45
Other Physicians, Lady Medical Officers, Medical Students, Interns (IDI and FGD)	136
Radiotherapists, technicians (IDI)	10
Nurses, Nursing Students, Paramedical Staff (IDI and FGD)	129
Chemists, Registered Medical Practitioners, Traditional Healers (IDI and FGD)	48
Researchers, Statisticians, Demographers (IDI)	14
Cytopathologists and Laboratory Personnel (IDI)	73

IDI – In-depth interviews
FGD – Focus group discussions

Table 3: Availability of Cervical Cancer Services in the Public Sector in Uttar Pradesh		
Health Care Level	***Description***	***Services Available***
First Referral Sites	rural community health centers, Primary health centers, and rural sub-centers	Only referrals of women with reproductive tract infections symptoms to district hospitals for Pap smears.
Second Referral Sites	Urban District Hospitals	A few Pap smears performed on symptomatic women, treatment of precancer (cryotherapy* available but hysterectomy was most often used). In many secondary referral sites, women just referred to tertiary facilities.
Tertiary Hospitals	Urban Medical Colleges and Universities	Pap-tests, colposcopy, Treatment of precancer (cryotherapy* available but hysterectomy was most commonly performed), cancer treatments (radical surgery, radiotherapy or chemotherapy).
Specialized Oncology Treatment Centers (Under National Cancer Control Program)	11 in Uttar Pradesh state, with one in Lucknow; none in Agra or Saharanpur	A range of cancer treatment services, including surgery, radiotherapy, chemotherapy.
**Cryotherapy equipment and supplies were available in some sites; however, they were mostly used for treating "cervical erosion" but not for the treatment of precancerous lesions.*		

Table 4: Average Cost in Rupees ($1=45 Rupees) by Sector of Various Cervical Cancer Prevention and Treatment Services			
Type of Service	***Public***	***Private (For-profit and NGOs)***	***Military***
Consultation	1	1-300	Free or minimal charge
Pap Collection and Cytology	0-13	36-300	Free or minimal charge
Colposcopy	50	500	Free or minimal charge
Cryotherapy/LEEP	50	500	Free or minimal charge
Cervical Biopsy	50	150-250	Free or minimal charge
Simply Hysterectomy	400	10,000-25,000	Free or minimal

			charge
Radiotherapy	900-5000	7,200-20,000	Free or minimal charge
Radical Surgery	400	25,000-40,000	Free or minimal charge

References

[1] Ferlay J, Bray F, Pisani P, Parkin DM: **GLOBOCAN 2002: Cancer Incidence, Mortality and Prevalence Worldwide**. *IARC Cancer Base* No. 5, version 2.0, IARC Press, Lyon, 2004

[2] Sankaranaryanan R, Buduk AM, Rajkumar R: **Effective Screening Programmes for Cervical Cancer in low- and middle-income developing countries.** *Bull. World Health Organ* 2001, 79 (10).

[3] National Intelligence Council: **The next wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India and China**. 2002. September, pg 3.

[4] National AIDS Control Organization, India. www.naco.online.org

[5] Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat. **World population prospects: the 2002 revision, highlights**, New York, 2003. February: 78-90.

[6] Chopra KF, Tyring SK. **The impact of the human immunodeficiency virus on the human papillomavirus epidemic.** *Arch Dermatol* 1997:**133** (5): 629-33.

[7] Sahasrabuddhe V, Makhija S. **Double jeopardy: HIV and cervical cancer in Indian women**. *Int. J. Gynecol. Cancer* 2005: **15** (1) 1-3

[8] International Agency for Research on Cancer (IARC) **Handbooks of Cancer Prevention Vol. 10: Cervix Cancer Screening**. 2005, IARC Lyon, France

[9] Rogo KO, Omany J, Onyango JN, Ojwang SB, Stendahl U. O. Carcinoma of the cervix in the African setting. *Int J Gynaecol Obstet 1990,* **33**:249–255

[10] Fonn S , Bloch, B., Mabina, M., Carpenter, S., Cronje, H., Maise, C., Bennun, M., du Toit, G., de Jonge, E., Manana, I., and Lindeque, G. **Prevalence of precancerous lesions and cervical cancer in South Africa—a multicentre study**, *S. Afr. Med. J.* 2002 **92** (2):148–156

[11] World Health Organization, Department of Reproductive Health and Research: *The Strategic Approach to Improving Reproductive Health Policies and Programmes*, Geneva 2002.

[12] Ministerio de Salud y Prevision, EngenderHealth and the Pan American Health Organization/World Health Organization: *Cervical Cancer Prevention and Treatment Services in Bolivia, A Strategic Assessment*, March 2003

[13] Bruce J. *Fundamental elements of quality of care: A simple framework.* Stud Fam Plann 1990, **21** (2):61-91.

[14] Huezo C, Diaz S. *Quality of care in family planning: Clients' rights and providers' needs*. Adv Contracept 1993, **9** (2):129-139

[15] Indian Council of Medical Research: *National Cancer Registry Programme*, August 2001.

[16] National Institute of Allergy and Infectious Diseases. *Scientific evidence on condom effectiveness for sexually transmitted disease (STD) prevention. Workshop summary*, June 2000