In: Cervical Cancer
Editor: Laurie Elit
ISBN: 978-1-62948-062-6

Chapter IV

Planning and Implementation of a Cervical Cancer Screening Program

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Abstract

Introduction: Implementing a national cervical cancer screening strategy must meet two conditions. First the incidence of cervical cancer must justify a screening programme and second, the necessary resource must be available and committed for attaining population coverage, and ensuring management of test positive cases. In this chapter, we will discuss the considerations that are important in implementing a cervical screening programme. Using the country of Mongolia, we will provide examples from their recent experience of implementing a national cervical screening program from 2009-2013 to demonstrate these considerations.

Methods: A literature search was conducted using MEDLINE and search terms including "cervical cancer screening", "program planning" and "programme implementation". Various key documents will provide insight into the Mongolian experience including the results of the STEP survey, KAP survey, individual and team reports to EPOS health management and the Millennium Challenge Corporation, and nation and aimag specific program plans.

Results: When introducing a cervical cancer prevention program, policy-level decisions and planning needs to address: 1. Women who are at risk for cervical cancer including their perspectives, socioculture issues, and education; 2. Technology including which screening test is to be implemented, safety, procedures and supplies, costs and

acceptability and 3. Services included policies, service availability, health information systems and health care providers. Once resources were secured to implement a national cervical screening program in Mongolia, a planning team (the Project Implementation Unit of the Mongolian Millennium Challenge Corporation) was identified. They were responsible to the Mongolian Ministry of Health. They engaged stake holders, analyzed the situation, developed national policies, guidelines and standards and obtain support for these. The planning phase of the project included engaging local stakeholders to assess local needs, build program capacity, launch and implement the program and then monitor and evaluate the program.

Conclusion: Rates of cervical cancer can be minimized when a cervical cancer screening program is effectively implemented nationally. This process involves engagement at both the policy and at a program management level. The recent implementation of such a program in Mongolia provides examples of options to consider when making program decisions at both levels.

Keywords: Cervical screening program implementation

List of Acronyms

DOH	Department of Health
EPOS	EPOS Health Management
FGP	Family group practice
GAP	Global Assistance Programme
LEEP	Loop electrosurgical excisional procedure
MCA	Millennium Challenge Account Mongolia
MCC	Millennium Challenge Corporation
MOH	Ministry of Health
NCC	National Cancer Centre
NCDI	Non-communicable diseases and injuries
NGO	Non-governmental organization
PIU	Program Implementation Unit
STDs	Sexually Transmitted Diseases
STEPs	WHO STEPwise approach to Surveillance
TMN	Tumor, Metastases, Nodes Classification System
UNFPA	United Nations Population Fund
URC	University Research Co., LLC
VIA	Visual Inspection with Acetic Acid
WHO	World Health Organization
Yo	Years old

May the *g*olden *l*ight *in* the *e*ternal *b*lue sky *of Mongolia*,
forever *shine* on the mothers and daughters of the Great Mongol Nation. [1]

Introduction

Cervical cancer is the third most common cancer in women worldwide accounting for 530,000 new cases and 275,000 deaths annually [2]. This is a tragedy as we have had the technology to identify the precancerous stages of the disease for at least 60 years (i.e. the Pap

test). Not only do we have screening tests that could help identify women with precancerous changes of the cervix (ie., Pap test, Visual inspection with acetic acid, and careHPV^{TM}), but we also have successful treatments to remove these abnormal cells (ie., cryotherapy, LEEP, laser ablation and cold knife cone biopsy) so as to prevent precancerous cells from becoming cancer. For the last decade, we have also had access to a vaccine which prevents acquisition of the two most common HPV types (16 and 18) that cause 70% of cervical cancers. The principals for implementing a cervical cancer screening program are the same whether you are in a low resource setting or in the developed world, as has been stated for instance by the WHO [3]: "A decision to implement early detection of cancer in health services should be evidence-based, with consideration for the public health importance of the disease, characteristics of early-detection tests, efficacy and cost-effectiveness of early detection, personnel requirements and the level of development of health services in a given setting. Even if the costs of the screening tests are relatively low, the whole process may involve substantial expense and may divert resources from other health care activities".

In this chapter, we will discuss the basic principles for developing or augmenting a cervical cancer screening program. We will liberally provide examples of these principals using our experience in the recently implemented national cervical cancer screening program in Mongolia.

Methods

A literature search was conducted with MEDLINE and GOOGLE using search terms such as 'program planning', 'program implementation' and 'cervical cancer screening'. The examples from the Mongolia cervical screening program were derived from meeting minutes, program reports, research reports from the Mongolian Ministry of Health, Mongolian Millennium Challenge Corporation, and EPOS Health Management.

Results

The Alliance for Cervical Cancer Prevention describes 3 phases in developing a cervical cancer screening program [4]. First there is the initiating or policy phase, then the planning phase and lastly the implementation phase. During the policy phase, there must be a defined need for a screening program based on an analysis of the extent of the problem and a high level of commitment toward developing a screening program. Engaging key stakeholders is critical to drive the process including developing laws, guidelines and standards that will guide the planning and delivery of the program. During the planning phase a program co-ordinator and multidisciplinary team are appointed and they focus on engaging local stakeholders, conducting a situational analysis to understand the training needs, equipment needs, and requirement of collaboration across services, and issues around community engagement. During the implementation phase, there will be a need for ongoing engagement with all stakeholders to ensure availability of the services, access of the services and establishing linkages and referral systems. Monitoring and evaluation will provide

information on gaps and successes. In this chapter, we will discuss in more detail, aspects of each of these 3 phases.

A. Policy Phase

When determining that a cervical screening program is needed and then building the components of that program, there are 4 areas that need to be addressed; confirm political commitment, engage stakeholders, conduct a situational analysis, and develop policies to govern services [4].

The first area to address is to confirm political commitment. In other words, there must be an ongoing commitment of high level decision-makers toward developing or strengthening a cervical cancer prevention program. This commitment is reflected by investing the necessary resources and designating a coordinator for cervical cancer prevention who has the mandate, authority and resources to direct the program.

Example:

In 2012, Mongolia was made up of 2.75 million people of which 61.8% lived in urban centres and 38.2% lived in rural areas. 1.071 million (39.2%) lived in the capital city – Ulaanbaatar. Mongolia was divided into 21 aimags (ie., provinces) and each aimag was divided into soums, and each soum was divided into baghs [5]. In 1992, Mongolia moved from a socialist framework in terms of its system of politics, economy, and healthcare. Since that time, their framework has shift to a market economy system with a more democratic political process; however, their healthcare reform has lagged behind.

The funding to develop the Mongolian Cervical Cancer Screening program came through a grant from the Millennium Challenge Corporation. In part the structure to develop the cervical cancer screening program was influenced by the contract of the grant. The Millennium Challenge Account Mongolia was a 5 year health project. It was launched in September 2008 (MCA-Mongolia). This compact made available $284.9 million dollars to reduce poverty in Mongolia through economic growth. The compact covered 6 projects: a property rights project, a peri-urban project, a technical and vocational education and training project, a health project, a north-south road project and an energy and environment project. In the health project the goal was to decrease mortality and disability due to non-communicable diseases and injuries (NCDIs) and thereby increasing the length and quality of life for Mongolians. The long term objective was to increase the productive lives of Mongolians. The short term objective was to increase access to information and services about noncommunicable diseases and injuries which would enable Mongolians to guard their health. The target population covered in the compact was working age Mongolian adults [6]. To this end, the $39 million USD in the health project was directed toward prevention and treatment of hypertension, diabetes, cervical and breast cancer, and road traffic accidents. In this chapter, we will focus on the development of the cervical cancer prevention program.

The second area to address in the Policy Phase involves engaging high-level stakeholders by involving policy makers [4]. Here senior individuals representing key groups will need to be identified. They are usually individuals involved in or affected by the cervical cancer prevention program (ie., decision makers in their own organization, senior MOH officials, heads of medical organizations, university professors, heads of relevant Non-Governmental Organizations (NGOs), high profile community leaders) [4].

Example:

The Mongolian cervical cancer prevention project was managed by the Health Project Implementation Unit (PIU) which was separate from but reported to the Mongolian Ministry of Health and international organizations. The PIU worked within existing structures in Mongolia including specialized organizations, Aimag Department of Health (DoH), training/research institutions (ie.,universities), and legal non-governmental organizations (ie., WHO, UNFPA) [6].

The third area to address is to conduct a situation analysis to determine the burden of disease and relative importance of cervical cancer compared to other health priorities [4]. This could include identifying existing services that could be utilized for a screening program and the technical resources that are available [4].

Example:

A STEPs survey [7] was conducted to understand the prevalence of non-communicable diseases and injuries and risk factors for these among adults. In 2008, the average life expectancy for a Mongolian was 67.2 years. In contrast, healthy life expectancy for Mongolians was 53 years old for men and 58 years old for women. The leading causes of death were cardiovascular disease and cancer [5]. Among cancer deaths, the leading causes of death for women were liver cancer followed by cervical cancer [5,9]. Since the predominant cause of liver cancer was hepatitis, and universal hepatitis B vaccine had been initiated in the country in 1991, interest now shifted to the prevention of cervical cancer [10]. The incidence of cervical cancer had risen from 17.8 per 100,000 in 2000 to 29.9 per 100,000 in 2008 [6]. Mortality had increased from 7 to 7.7 per 100,000 during this time [10]. Seventy-five percent of women presented with Stage 3 and 4 disease resulting in a high case fatality rate. Ninety-one percent of women were diagnosed between 35-55 year old during their reproductive year and economically productive years [10].One major contributor to the high and increasing occurrence rate be the endemically high HPV infection rate reported between 35% and 46% in sexually active women and reaching almost 50% below the age of 25[11,12].

The fourth area to address in the Policy Phase is to develop a policy that will govern the cervical cancer prevention services [4]. This includes identifying the screening test, the target age group for screening, the desired population coverage, the screening frequency, appropriate provider licensing, and whether the program will be a vertical or integrated program within the health services. A vertical program means the health care providers and facilities are devoted to only one health care service (cervical cancer screening). An integrated program means that the client can access more than one health service at the same facility on the same day and from the same health care provider (ie., imbedding cervical screening in to primary care clinics. The strengths and limitations of both approaches will be discussed later in the chapter). The World Health Organization (WHO) recommends that a cervical screening program begin by screening women aged 35-50 years old at least once in a life time before expanding the services and providing repeated screening (ie., once in every 10 years). They also recommend providing a screening test with high sensitivity and treat women with high grade dysplasia and cancer [13].

Example:

A Rapid Needs Assessment was performed in 2009-2010[9] and showed that there was a Mongolian National Cancer Plan but this had not been implemented. There was a National Palliative Care Plan (N37, 2005) which called for 5 palliative care beds in each region

according to population [9]. There were palliative care resolutions in the master program of the Ministry of Health 2006-2015 (N72, 2005), the National program on Non-Communicable Diseases (N246, 2005) as well as the Health Law of Mongolia (2006.01.19-paragraph 28 part 1.6)[9]. There was a Document Sub-Programme on Cancer Prevention and Control. 2009 and the Ministry Of Health (MOH) authorized its implementation on 18 Sep 2008 Order of the Minister No 210; however, where cervical cancer prevention was concerned, many of the current technologies, like LEEP, were not available in the country. Thus the Ministry of Health (MOH) gave an order (March 2010) to convene a Cervical Cancer Prevention, Treatment and Palliation Guidelines Working Group. It involved 2 external consultants (Lars Elffors, Laurie Elit), a representative of the National Cancer Centre (G Purevsuren) and several other representatives from local STEs, National Cancer Center (NCC), and other national institutions. The Cervical Cancer Prevention, Diagnosis, Treatment and Palliation Guideline was created in English and back translated into Mongolian. The final guideline document was approved December 1, 2010 as Cervical Cancer Guideline protocol No 020/034 [14,15]. Specific guidelines for pain management in palliative care were also developed, as the first step toward holistic palliative care guidelines, as required by the WHO.

Some of the specific issues that the guideline group grappled with included: the test, the age group to be screened, the frequency of the screening, and management of test positive cases. There was extensive external international assessment-recommendation process. Regarding the test and the age group to be tested, the international recommendations (URC, EPOS Health Management, UNFPA) were for cervical screening of women aged 30-60 year old initially with VIA [9].Three implementation strategies were put forward including: screen all women ages 30 to 59 year old with once in a lifetime VIA which would mean the program needed to reach 485,000 women and 145,000 each subsequent year (assuming 90% coverage). A second strategy involved screening women at age 30 and again at 35 yo. This meant screening 30,000 women initially and 27,000 each year (assuming 90% coverage). A third strategy involved screening women on at age 35 yo which would involve 15,000 women initially and 13,500 each year (assuming 90% coverage). There was a small experience in Mongolia with both Pap test (NCC, private clinics) and VIA [16,17]. Some of the concerns with this approach were the lack of gynaecologists to deal with the high number of expected test positive cases. Using a second test (such as a Pap test or careHPV) was proposed. A proposal at an early stage, to use VIA as a screening instrument, but followed by further assessment, rather than direct treatment was rejected due to the assumed very high rate of false positive results (low specificity), which would bring strain to the very few available pathologists in the country. Concerning the Pap test, the issue was a lack of trained cytologists and cytotechnologists in the country. Concerning careHPV, it was felt to be too expensive. After many meetings, a subcommittee of 12 Mongolian leaders (Specialist in charge of Obstetrics and Gynecology services in the MOH, representative of the Government Implementation agency, vice director of the National Cancer Centre, vice direction of the Ulaanbaatar city Health Department, co-ordinator for UNFPA health reproductive project, Head of cancer research at NCC, head of Gyn-oncology surgery at NCC, head of pathology at NCC, senior chest surgeon at NCC, gynaecologist at NCC, Head of a family practice group No 10, Head of Mongolian Family Clinic Association) recommended the Pap test as the screening test and that cytology capacity be developed throughout the country. They recommended that test positive cases should be evaluated with colposcopy and treated with

Loop Electrosurgical Excisional Procedure (LEEP). Thus, this was the strategy put forward in the national guidelines.

The Mongolian cervical cancer screening policy was planned to be integrated into the public health system of level 1 clinics [5]. Ultimately the Department of Health in each aimag was designated as responsible for the cervical screening program. The Aimag Department of Health would use census lists or lists of populations from the Primary Health Care Centres to identify eligible women. Trained family health workers would visit homes of individual women. Women were invited both verbally and by written invitation to specific family practice clinics based on their address (or job ie., women working on the railroad/army would be seen at the respective railroad/army hospital). The family health workers would issue a screening card to eligible women with her name, age and address filled in. They would also maintain a register of all women invited to participate. Each clinics developed strategies for how screening was delivered (ie., family practice clinics would general offer cervical screening two days a week and Aimag centres would offer screening every day of the week). This information was printed on the invitation card. Women with abnormal results would be referred to the nearest colposcopy clinic usually located at the Aimag hospital or Regional Cancer Diagnostic Centre. All demographic, screening, cytology, and diagnosis information was held within the Aimag Department of Health. A specific call/recall system was designed and developed in order to manage the women as well as the data. This was, however, not yet working properly six months into the full-scale implementation of the policy.

One of the issues encountered involved terminology. Some of the cytology and histology terms in the English document did not have equivalent terms in Mongolian. Thus the Health Sciences University of Mongolia Medical Terminology Committee had to be involved to amend and ultimately approved terminology used in the guidelines protocol No 10/10 from Nov 12, 2010 [14].

Ultimately the following ordinances were passed by the Ministry of Health:

Ordinance #292 (2010) Improve the capacity for prevention of cancer in aimags and district; Ordinance #168 (2011) Cervical cancer guideline(CG-4); Ordinance #76 (2013) Registry statistical guideline (SG-1),Recall system statistical guideline(SG-2), Cancer Palliative Care guidelines (CG-6), Ordinance #96 (2013) Approval of national and local implementation plans, Ordinance #208 (2012) Distribution of equipment like cytology stains, Ordinance #242 (2012) Handling of Drugs [18,19].

A Standards of Practice document in Mongolia describes in detail the tasks various health providers are allowed to perform. Although these existed prior to the development of cervical screening guidelines, this had to be amended to reflect the evolving functions of various disciplines like performing LEEP for gynaecologists (MNS 5855-2:2008)and Cervical Cancer early detection, case management and followup (MNS 5855.2.2011) [14,20,21,22,23]

B. Planning Phase

The second aspect in developing a cervical screening program involves planning the program by engaging local stakeholders, assessing local needs and developing a program action plan. Once these tasks are complete, the management team could aim to build capacity for the program and prepare for implementation [4]. Cervical cancer screening involves many

facets: Community information and education increases awareness about cervical cancer and preventative health screening behaviours; screening services including clinics where the test can be completed and cytology laboratory where the test can be analyzed; diagnosis and treatment services for women with a precancer or cancer diagnosis including histopathology laboratory; training for staff in all settings; and monitoring and evaluation [4]. There is interaction of all of these facets for example, the cytology specimen must get from where it was retrieved to the cytology lab. Also the results of the cytology specimen must get back to the health care provider and ultimately the woman who was screening. Planning the program recognizes the there are women in a community who are in the recommended screening cohort, and health care providers who deliver the screening service and follow-up of women with positive tests. Some of the key aspects during this phase involves an assessment of the services currently available including equipment and facilities, training needs for health care provides, and knowledge attitudes and behaviour of the women and their community. Once the assessment is conducted there must be a plan to augment services where needed.

The first aspect in the planning phase involves training. The goal of training is to ensure that there is a sufficient number of competent staff to provide the various aspects of the screening service to eligible women including those identified as having precancer and cancer [4]. Training can involve health care provides like family doctors, gynaecologists and nurses, but it may also include statisticians, clerical staff, cleaning staff, community health workers and biomedical engineers.

Example:

Assessment: The Rapid Needs Assessment [10] done in Mongolia showed that there were deficits in knowledge and understanding about cervical cancer prevention among primary health care providers and their staff, a deficit in number of gynaecologists who could perform colposcopy and treatment of precancers, and a lack of cytologists.

Intervention: Training was undertaken using a train-the-trainer model. Here international and national experts trained an educator and regionally identified peer leaders in their field (Figure 1,2). The educator along with these trained individuals delivered the training in their regions and the surrounding regions using the same material including printed materials, slide decks and videos. The number of individuals to be trained, the length of training and responsible individuals were identified centrally by the PIU. The individuals to be trained were recommended by the regional department of health with input from the local clinics, hospitals ect. Discipline specific training modules were developed (spring 2010), pilot tested (summer-fall 2010) [14] and then implemented with smaller core groups (fall –winter2010) and then eventually across the country (spring- summer 2011). These included both didactic, small group and practical sessions. Although the training emphasized training in the knowledge and skills related to the paradigm of cervical cancer prevention, given results of the community assessment (presented later in this chapter), there was focused training on counselling clients prior to, during and after the medical encounter [24,25]. This counselling involved establishing a respectful rapport with women and addressing their fears and concerns. This was felt to be important in order to encourage women to return for follow-up visits [24,25]. Pre and post tests showed considerable improvement in knowledge (increased by 25%) [10,14,24]. In order to expand the cytology capacity in Mongolia, interested family physicians nominated by their aimag, were brought to the National Cancer Centre (NCC) cytology lab where they underwent an intensive 2 months of didactic and practical training before returning to their Aimag hospital. After this time, case conferencing

was possible with the NCC through a telemedicine linkage with the NCC [26]. Separate atlases/training sets (Figure 3,4) were created/translated for colposcopy [27] and cytology [14].

Figure 1. Class picture of physicians attending the January 2011 colposcopy training.

Figure 2. Colposcopy training practicing electrosurgery on a chicken breast.

Figure 3. Colposcopy training book developed in conjunction with IARC [27]. The book was translated into Mongolia with permission from IARC.

Figure 4. Manual created in Mongolian language for training cytotechnologist.

The second aspect of the planning phase involves facilities and equipment. Preparing and sustaining service facilities means that the screening and treatment services need to have designated space that meets certain requirements (ie., ventilation options for smoke evacuation when a treatment is performed by LEEP). The space also needs to be stocked with appropriate type and volume of supplies and equipment. In addition, strategies must be defined to minimize damage to expensive equipment (ie., surge protectors to prevent power surges). Policies and procedures need to be developed around cleaning the equipment. Procedures are also needed to define individuals who will procure supplies; document receipt of these and problem solve incomplete orders. A strategy of waste management needs to be put into place.

Example:

Background: Health care in Mongolia is organized along a primary, secondary and tertiary system of care [5,21]. Mongolia is made up of 21 aimags (provinces), which are divided into 338 soums (districts) which are further divided into baghs (villages).Primary care is offered by bagh feldshers (ie., health care workers and midwives), family group practice (FGP) clinics or family health centre of which there are 228 across the country and soum health centres and inter soum hospitals (35 in the country). Secondary care is offered at District General Hospitals and Aimag General Hospitals. Tertiary level care is available in UlaanBaatar where there are major hospitals and specialized professional centres like the National Cancer Centre (NCC) and Regional Diagnostic and Treatment Centres (3 in the country) [5].

In the 1990s, the only cancer treatment (ie., radiation, curative surgery and chemotherapy) was available at the NCC. In the last decade, 3 regional Cancer Diagnostic and Treatment Centres were developed as a place closer to home where patients could be assessed and if they have a potentially curative cancer referred to the NCC [29]. If the cancer was considered palliative, then the pain and symptom management, if offered via oncologists, could be administered at these regional centres, closer to home.

Assessment: A Facilities Based Impact assessment [10] showed that all centres were lacking in the equipment necessary for screening (ie., speculums, preservatives). The labs were lacking in Pap test stains. The Hospitals and Regional Diagnostic and Treatment Centres did not have operable colposcopes, biopsy forcepts, or LEEP/cryotherapy units [10]. The units that were present had been procured originally from international donors [10].

Intervention: One of the priorities of the project was to define the type and amount of equipment needed at each service level. Unfortunately delivery of procured equipment which was planned for early 2011, was delayed until the spring of 2012.

Part of one's care is paid for by the national insurance but people must contribute to the cost of their care. Prior to the MCC project, Pap tests were designated to be paid for by the individual. During the conduct of the project, one Pap test per woman age 30-60 years old was free.

There are two aspects of the Planning Phase that are related to the education of women and the community. First involves the broader scope of educating the community about cervical cancer and the opportunity to prevent this disease through vaccination and screening. Second involves the one on one counselling with a woman at the time when she is considering or presents for the screening test.

Educating the community: It is important to have an information and education plan that informs women in the target age group and their partners about the benefits and availability of

cervical cancer prevention services. This plan focuses communication at different levels such as the community, facilities and media. Although the media can reach a large proportion of the community at one period in time, its impact is different than that of direct contact with health workers and peer educators. Group awareness followed by individual counselling can address a client's specific informational and emotional needs, motivate her to follow treatment recommendations and establish a satisfied client who will encourage other women to attend screening. Printed material is helpful to reinforce messages but should not replace direct provider contact.

Educating individual women: Since the women at highest risk for cervical cancer usually have completed childbearing and so are unlikely to access family planning or maternal health services – special approaches for screening are required [30]. Creating culturally relevant methods are needed (ie., through input from local women's or community groups); by linking screening to an important event in an older woman's life (ie., becoming a grandmother) or linking screening to other mid-life events (ie contraceptive sterilization). Use of multiple communication strategies is most successful [30]. The most valued education comes from the physician to the woman and this interaction strongly influences whether the woman returns for her follow-up or rescreening appointments. The interaction with a physician should take place in a private and safe place for the woman.

Example:

Assessment: In Mongolia there were several types of assessments used to understand the knowledge, attitudes, beliefs, and behaviour of women and their partners concerning cervical cancer and cervical cancer screening

A cross-sectional survey was conducted in 2009 using the WHO STEPS survey methodology [8]. A total of 3,221 women were randomly selected from ages 15-64 years old. Mongolians participated from 36 soums of 20 aimags and 6 Ulaanbaatar city districts. The demographics of the women were that 6.9% (5.2-8.5%) currently smoke usually starting at 23.2 (21.3-25.1) years. The population included 496 aged 15-24yo, 992 aged 25-34 yo, 876 age 35-44yo, 626 age 45-54 yo, and 301 age 55-64yo. The mean number of years of education was 10.8 year. Women were more likely than men to have post-secondary school education. The average annual income was 1,282 USD. Cervical cancer screening coverage was reported to be very low; 5.2% (95%CI 4.2-6.1%) of females surveyed reported having had a VIA test and 11.4% (95%CI 9.9-13%) a Pap test. The highest cervical screening rate was in women 35-54 years old. Cervical screening coverage was the same in urban and rural settings.

A qualitative study was conducted through Mongolia involving women ages 30-60 years old and their husbands [6,7]. The women in the study either presented for cervical screening or were diagnosed with cancer. They either had a one on one interview or they were interviewed in focus groups. The first theme involved female knowledge, attitudes, behaviour and perceptions of risk factors related to cervical cancer screening. Women appeared to know about cervical cancer if a family member or acquaintance was affected. Rural women appeared to present in the late stages of the disease. Women reported higher satisfaction with treatment at the NCC with a lower complication rate than women treated at private clinics. Women reported a lack of information about cervical cancer and its cure rates. There was a considerable difference in knowledge levels between urban and rural women; for example, rural women thought the causes of cervical cancer were smoking, heavy drinking, complicated delivery, stress and chronic illness. Urban women thought the causes were not

being faithful to husband, multiple sex partners, early age of sex, abortions, STD, husband's education level. The second theme involved the perceptions, misconceptions and knowledge of signs and symptoms of cervical cancer as pain, bleeding, and discharge. Women found it hard to tell their husbands this was going on, but when they did tell their husbands they were encouraged to get medical care. The third theme was perceptions, knowledge, and attitudes related to screening. Urban women found it easier to seek health care from private clinic even though its more expensive. Rural women went to local hospitals for treatment. Most women did not know anything about cervical cancer screening. Women claimed that health providers do not give information about screening. The fourth theme was the experience with screening and referral. Women found the waiting rooms of screening service locations crowded, inconvenient and they lack information about cervical cancer. In urban centres, the husbands came with the women and helped in decision making. In rural settings women came to the hospital alone. MDs do not explain things, too busy.

A cross-sectional survey of knowledge, attitudes and practices related to non-communicable diseases among Mongolian general population was conducted in 2010 [31]. This survey included 2,037 randomly selected women ages 15-64 yo from 24 soums of 20 Aimags and 18 Khoroos of 7 districts of Ulaanbaatar. Data was collected in 2010. 594 were ages 15-24yo, 441 wee 25-34 yo, 396 were 35-44 yo, 311 were 45-54 yo, and 295 were 55-64 yo. 11.9% of women complete college and 25.7 completed university. 22.2% of women were employed in the public organizations, 6.7% in NGOS, 18.1% in private sector and 1.2% irregular employment, with 16.1% unemployed. More than half of the women 30 yr and older (57.6%) did not know about cervical cancer. The 4-point scale showed that 22.1% (18.1-26.6%) had no understanding, 35.5% (30.7-40.7%) had heard the term, 31.5% (28.1-35.1%) know a little, and 10.9% (8.2-14.3%) knew it well.21.4% did not know how often to have a Pap test and 71.6% (66.6-76.1%) thought it should occur annually, 6% (4.1-8.8) every 3years, 1% (0.5-1.9) every 5 years. Reasons for not having a Pap test were that 63.1% (58.1-67.9) did not know that they needed a Pap test and 14.5% (11.4-18.2) said they did not have time while 13.2% (10-17.4) did not know where to go to get a Pap test, 2.5% (1.4-4.4) said it was expensive and 2.1% (0.8-5.5%) said it was embarrassing. In terms of prevention: 15.3% (said it was preventable by vaccine and 84.7% said it was not preventable. Responses were similar in rural and urban women. 45.7% (39.9-51.7%) said they never worry that cervical cancer could affect them or their families, and 48.4% (43.4-53.5) said they seldom worry about this while 5.8% (3.9-8.6) were very worried. Women have a lack of knowledge about cervical cancer and thus have a low risk perception. They have lack of a risk perception leading to a lack of preventive behaviour. This study showed a need to develop a nation wide education and health promotion.

The School of Public Health in Mongolia did a health seeking behaviour study involving six hundred and thirty four teachers from 60 schools in 2010 [32]. These teachers were predominantly female (90.2%) and represented urban (49%) and rural schools (51%). Mean age was 37.2 year. 93.7% considered cervical cancer preventable. 40.5% named the Pap test as a method for early detection while 3.6% named colposcopy as a method for early detection. Knowledge about cervical cancer and screening appeared to be better in educated women.

Intervention: A multipronged approach was planned around education of Mongolians concerning cervical cancer and preventative health care.

Opportunistic Media opportunities: The media coverage concerning the success of receiving the Millennium Challenge project in Mongolia in and of itself raised awareness about health issues in Mongolia. During the time frame of the Millennium Challenge project, the first lady of Mongolia who was also involved in the Hope Foundation, was instrumental in procuring the HPV vaccine through GAP for Mongolian girls aged 14yo. This also resulted in media attention which further educated the public on primary prevention and cervical cancer.

Planned educational events: The project planned for time on national television to provide in depth education on the need for screening to prevent cervical cancer. In addition, at each health clinic offering cervical screening there were large posters hung either outside the clinic or on the clinic walls in the waiting area (Figure 5). These serve to reinforce the message about the importance of cervical screening. Family health workers were trained concerning cervical cancer risks and prevention strategies. Family health workers were instrumental in handing out the invitations for cervical cancer screening and were often the first level of trained personnel that the Mongolia general public interacted with one on one concerning information needs or specific questions related to cervical cancer prevention (Figure 6,7,8). Nurses and doctors were trained in counselling concerning the Pap test and giving results. This model of educating and counselling patients was novel for many health care providers.

Figure 5. An example of posters on cervical screening found in family practice clinics.

Figure 6. An example of an invitation card for the Kazak region.

The fourth aspect of the Planning Phase related to information systems. In order to understand how well the cervical screening program is functioning, the program requires good records whether paper based or electronic. Ideally the system should be able to identify who needs to be invited to be screened and track their results, including the test positive cases that required further investigations and treatment. Indicators like screening coverage can be determined with access to such information and allows the program management team to focus on specific issues that are identified.

Example:

Assessment: Prior to developing the Mongolian Cervical Screening Program, every Mongolian had a 6"x 8" paper based medical record that they were personally responsible for. This record and any ancillary pieces of paper with test results or XRay films were carried by the patient from health care provider to health care provider. During the time frame of this project, cell phone use was possible throughout most of the country. Although internet was available throughout the country, it was exceedingly slow and costly especially in more rural locations.

Plan: National standardized screening invitation logs and screening participation logs were developed. National data collection forms were developed for lab results (ie., cytology and histology), and clinical assessment (Pap test completed, colposcopy record, treatment record). One copy would follow the patient but one copy would go to the Aimag Department of Health either in paper or by electronic data capture. When data capture did not occur directly at the clinic/lab, these results would be transferred from paper based forms into an electronic system specifically created for cervical screening program by the statistics department at the Aimag Department of Health [14,15].

During the creation of a strategy for data collection for the cervical screening program, it became clear that the National Cancer Registry which is a part of the National Cancer Centre and is regulated by a HM Order no 203 2005 [33] was not operating optimally. In part this was due to multiple issues including incompatibility of the CANREG 5 system to the in country hardware and the lack of a Mongolian translation of morphology coding and TMN classification. Thus, Mongolian cancer statistics only reflected data from patients who were seen and registered at the National Cancer Centre and not about cancers occurring throughout the country. This cervical screening project created an opportunity to improve upon the status of the national cancer registry.

C. Implementation Phase

The third phase of developing a cervical cancer prevention program involves a plan for implementing, monitoring and evaluation [4]. All the work of the policy and the planning phase comes to fruition during the launch of the program. As discussed above, the components of the program include providing the community with information and education to address both the community and client's needs; delivery of the clinical services and the linkages between services; and ensuring trained providers are performing to standard [4]. Once the program is operational, ongoing monitoring is focused on ensuring that quality services are provided and taking time to collect and analyze data related to the program's goals and taking timely corrective action to optimize quality of care. This may be at the local level, the regional level or the national level. Evaluation is a formal process of measuring indicators to determine if the program is meeting its goals including the reduction of advanced stage cervical cancer (an outcome variable). As part of implementation, the management team works toward ensuring the availability of service, ensuring access to services, and maintaining linkages and referral systems.

Example:

In Mongolia, each aimag Department of Health received a Cervical Cancer Screening Manual. This manual included: 1.The cervical cancer screening guideline, 2.Procedures, 3. Standards (ie., how to label Pap test slides with the patient identifiers), 4. Instructions related to equipment like cleaning and maintenance, 5 Waste management protocols, 6. Standards for the size of the room and equipment requirements, 7. Human resources in terms of number and type of personnel required with their job description, 8. Equipment lists, 9. Quality assurance plan, and 10. The monitoring and evaluation plan.

There were implementation plans for both the national and locoregional level. These outlined in detail the 1.Human resources issues; 2. Guidelines, standards and procedure protocols, 3. Supplies and Equipment, 4. Facilities, 5. Data registry and call back, 6. Community Education, and 7. Monitoring and Evaluation. Each item had a list of activities to be accomplished, time frame, agency responsible, a list of cooperating agencies, expected outcomes, and indicator(s). By and large the national plan was under the direction of the MOH and PIU. The locoregional plan was under the direction of the Department of Health.

The first aspect of implementation involves ensuring availability of services for all women in the target age. Within this section all components for cervical cancer prevention must be in place and functioning including all components of the clinical service (counselling, screening, laboratory services (cytology and histology), diagnosis (colposcopy) and treatment

of precancer (LEEP), post treatment followup, a referral system for treatment of cancer or end stage disease (palliative care)). This task also involves focusing on making sure appropriate staff is available and trained at every level of care. It also means preparing and sustaining facilities for the task that they have been designated to conduct.

Example:

Each family practice/public health clinic needed to define how the Pap test specimens would go to the lab. In one centre this meant the nurse would walk the specimen to the lab when she walked home from work. In rural settings, there was discussion that a multi-use driver would pick up and deliver the specimens on a weekly schedule. Each jurisdiction problem solved the portion of the program that was under their control.

Figure 7. In one clinic, this is a survey of the households served by that clinic. The green dots represent who has been invited to participate.

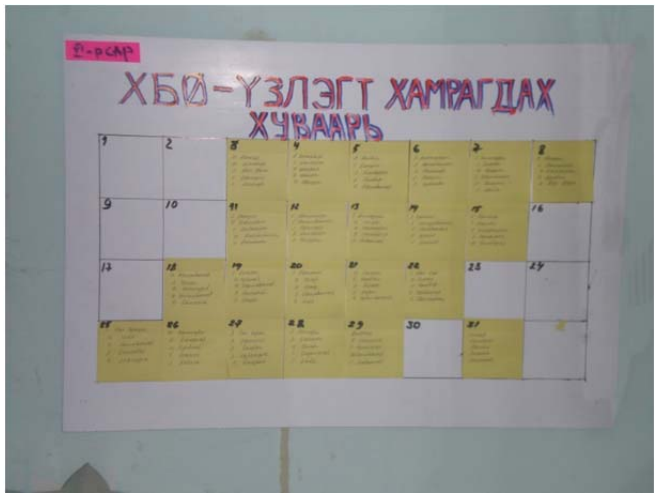

Figure 8. To handle the increase of patient volume, this clinic created a list of women who would be invited to attend screening each day of the month.

The second aspect involved in implementation involves ensuring access to cervical cancer prevention services. There are several strategies to optimize the chance a woman gets the care she needs which involves decreasing barriers [4]. A strategy of single visit versus multi-visit approach can minimize the number of health care visits for the woman screened. For example, a "see and treat" approach where screening and treatment take place at the same visit is a beneficial strategy for rural women and minimizes loss to follow-up due to geographic barriers to care. The multi-visit approach is associated with additional recalls and revisits for diagnostic evaluation and treatment and may pose added logistic difficulties. These may act as barriers to participation in the program [13]. Another consideration with respect to implementing the service involves a vertical versus integrated service. A *vertical service* means that clinics are run with the sole purpose of offering cervical cancer screening means that the staff roles and responsibilities are clearly defined but is more costly to implement and more difficult for the client to access. *Integrating* cervical cancer prevention services with other health programs that offer related services and/or reach women in their 30-40s [4,30] has the benefits of dealing with several health problems during one visit, using existing referral networks, and access to a wider range of onsite staff. A disadvantage of the integrated service is that there are competing priorities and prevention always seems less important than treating illness. An integrated service requires a higher level of planning and organization. It has the potential to excessively increase the providers' workload. The clinic staff's roles and responsibilities may be less well defined. Another strategy for implementing the service involves *static services* such as going clinics compared to high coverage onetime event outreach clinics like the Pap test bus.

Example:

The Mongolia MOH ultimately agreed to the choice of a multiple visit cervical screening approach. It was well known that this approach has many opportunities for loss to follow-up (ie., patient needs to return to get her results, patient needs to travel to a colposcopy clinic for diagnosis, patient needs to attend the colposcopy clinic for her results, the patient needs to attend the colposcopy clinic for treatment). In part loss to follow-up is related to geography (ie., distance from home to clinic), and other pressing priorities for the woman (ie., child care or work). The recently completed Healthy Mongolian project [9,17] showed some of the difficulties of carrying out a multiple visit cervical screening approach. In the Healthy Mongolian project, women were screened for cervical cancer using a questionnaire and/or VIA. 2,919 women were recommended to have further assessment. Only 332 (1 in 9) were confirmed while the rest (8 of 9) never attended follow up [9]. Mongolia did choose an integrated approach of including cervical cancer screening within the family practice model currently accessible throughout the country. This was augmented by the work being done by one of the NGOs known as the Daffodil project. Here the rotary club has volunteers who provide Pap test screening services to geographically isolated women [34].

As part of ensuring access to the cervical cancer screening program, there is a need to identify and address bottlenecks to effective service delivery [30].

Example:

Given that screening was an entirely new concept for most Mongolians and because the first Pap test would be free of charge, it was anticipated that many women would want the service. In order not to overwhelm health care providers including family practice/public health offices and cytology services, several implementation strategies were discussed. For example, there could be a once in a life time invitation of all women aged 30-60 years old to

attend screening when the service was ready to start. Alternatively, women could be invited during the month of their birthday to attend the service which would spread out the demand over 12 months. Alternatively, the first year of the program women 30-39 yo could be invited and the next year40-49 yo, and the final year women 50-59 yo could be invited. Alternatively since screening was to take place every three years, women aged 30, 33, 36, 39, 42, 45,48, 51, 54,57,60 yo could be invited to attend screening during the month of their birthday and this would smooth out attendance for a new service over the 3 year initiation. The last strategy was chosen in Mongolia [35].

The third aspect of implementation involves establishing and maintaining linkages and referral systems. A well-functioning referral network facilitates issues such as where the Pap test is analyzed, where the regional colposcopy clinic is located and its days and times of operation, how data flows between providers and how the system interacts with the community. Referral systems for patients with a newly diagnosed early stage cancer and end stage cancer are important. Within this system there needs to be methods of two-way communication, protocols for referral, tools like standardized referral letters and counter-referral letters.

Monitoring and evaluation helps determine whether the program is meeting its goals and objectives. Monitoring is about ensuring high quality processes of care. Monitoring determines whether the program is delivering appropriate services, reaching the women at risk (coverage) and allows for correction of problems in the operation of the program [4,30]. The outputs of monitoring include creating a quality service with available screening and treatment services run by competent staff and a community that is knowledgeable about cervical cancer. Evaluation is about being effective. Here questions are answered including: what is the screening coverage, what is the treatment rate of women with precancers. The ultimate goal is a decrease rate in late stage cervical cancer and eventually a decrease rate in all cervical cancers. Positive results in monitoring and evaluation can mobilize continued financial and political support for the program [30].

Example:

An example of monitoring in Mongolia involved the initial program launched in Tuv aimag. This was planned as a pilot study to identify key issues and rectify them so that later in the winter of 2012, the launch of the national cervical screening program would be more smooth. Another example of monitoring took place in the summer and fall of 2012. Here several individuals representing, health care providers, trainers, equipment, and health services planners conducted monitoring visits throughout the country. One focus was to verify that the equipment had arrived, was accounted for and operational. Another focus was to evaluate whether the health care staff understood how to complete forms and patient logs, and that the DOH statisticians understood the importance of timely data entry. Processes were reviewed at every level of the screening chain of events to ensure that each level had a plan and that those involved understood the plan.

The cervical screening program began in August 2012. The first 5 months of the program was evaluated and results discussed at the Second International Conference of Prevention and Control of Major non-communicable diseases and Injuries in May 2013.

1. *Knowledge Attitudes and Practice study from 2010 was compared to 2013. Here women of mean age 15-64 years old were surveyed and one of the questions involved awareness of cervical cancer. 54.2% of women had attended cervical screening. The*

awareness of the need for a Pap test had increased from 6% in 2010 to 34.2% in 2013, p<0.01. Awareness of the ability of a vaccine to prevent cervical cancer improved from 15.3% in 2010 to 45.3% in 2013, p<0.01.

2. *The Facilities Based Impact Study from 2010 was repeated in 2013. 88 urban facilities and 98 rural facilities were involved. There were 10 questionnaires completes by primary care practitioners, feldshers and nurses and managers or coordinators. On a 4 point score ranging from sufficient, middle, low, and insufficient, the overall score was sufficient. In terms of trained staff 78.7% scored sufficient; screening activity 85.1% scored sufficient; availability of guidelines 81.4% scored sufficient; available health education material 37.2% scored sufficient; and access to equipment 68.8% scored sufficient.*
3. *Knowledge, Attitudes and Practice study in school teachers involved urban regions (9 districts of Ulaanbaatar and 2 major cities), and rural areas (16 aimags and 9 soums). In 2010, 40.5% of teachers knew about Pap test and this rose to 71.60% in 2013.*
4. *Using the electronic data capture system, the coverage of invited women 30-60 year old for the first 5 months of the national program was 29.9%.*

It must be high-lighted, that there myst be clear ownership and management of a public health policy during the implementation phase, to ensure sustainability. A high-level Committee, provided with professional, political and financial authority must govern the implementation, monitoring and evaluating it, assuring quality and rapidly responding to any malfunctioning. This has been stressed as a necessary prerequisite for cancer screening programmes, particularly in low- and middle-resource health systems, by the WHO [3].

Example:

The recall system was developed for three purposes:

1. *To manage flows of patients and data through the screening process, according to the screening algorithms and Guidelines on cervical cancer*
2. *To deliver health data and data on the health system's performance for statistical analyses*
3. *To monitor the process and identify malfunctioning, bottle-necks and misunder-standings, in order to correct them*

It was early requested, and several times repeated, by the Project implementer, that a standing "Monitoring Committee" should be formed, already before the start of the implementation phase, with the tasks to actively monitor and evaluate the policy implementation, to collect and analyze data, and to promptly take any necessary actions of correction, whenever needed.

Almost one year into the implementation, such a Committee had yet not been formed, and it was not clear whether the Mongolian health system had understood the importance. As a result, data from the recall system had yet not been processed, and there was no clear understanding on how the policy was running. During a mission from the international cancer screening expert, data were processed and analyzed, together with the Mongolian counterpart, in a hands-on demonstration.

When this Chapter is written, there is finally a decision taken to follow the recommendations to harbour the policy on the MOH level (ownership),and to nominate a management for Monitoring and Evaluation, and Quality Assurance.

Conclusion

Creating or changing a cervical cancer program is not a unidirectional path of activity. It involves empowering a manager who sets into action the project plan which has clear objectives and timelines. This manager is ultimately responsible for the daily operations of the program. There is an interdisciplinary management team which is involved in raising concerns and problem solving issues. A clearly defined ownership and a staged management is a must in the implementation and maintenance of any public health policy. This clear ownership and firm management can minimize flaws in the systems that go undetected. In a national cervical screening program, there are also many stakeholders and partnerships. A change in one area has predictable and unpredictable ramifications. Thus communication is a key skill set in the leadership of the cervical cancer screening program. The plan and ongoing communication and problem solving will allow all the players to move forward there part of the cervical screening program plan. Monitory and evaluation will be critical to inform the successes and identify problems to information areas where adjustments are needed so that the ultimate goal (decreasing the rate of cervical cancer) is reached.

Next Steps

It is early days in the Mongolian cervical cancer screening program. The Mongolian Ministry of Health will need to continue to invest financially in the cervical screening program when the Millennium Challenge project comes to a close in September 2013. Identification of a responsible agency within the MOH has yet to occur. Monitoring will be needed to understand local issues and help problem solve these. Evaluation will be needed on an ongoing basis to determine if the rates of cervical cancer actually decrease with the screening strategy that was implemented. Location and responsibility for the electronic health record and recall system has yet to be defined. Mongolian office the WHO has indicated strong support for navigating this transition process.

Afterward

My Mongolian counterparts in the healthcare sector recently asked me, "Do you remember when you first came to Mongolia in 1999? You gave a lecture on cervical cancer prevention and most of us had never heard about a Pap test." It has been an amazing journey to participate, however, small in the implementation of a National Mongolian Cervical Cancer screening strategy. How well this program meets the needs of the Mongolian women at risk for cervical cancer is a story that will be written using the creativity, ingenuity and perseverance that the Mongolians have been known for since the time of their ancestors like Ghenghis Khan.

Acknowledgments

The Mongolian project was financed by the Millennium Challenge Corporation, USA, implemented by MCA-Mongolia and the institutional contractor was EPOS Health Management, Germany.

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