Report on Health Seeking Behavior
with regard to Cervical Cancer Screening
in Ulaanbaatar

Millennium Challenge Account-Mongolia Health Project
School of Public Health, Health Sciences of Mongolia

Ulaanbaatar, 2010
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</tbody>
</table>

**Research team:**

**Advisor:** Juliette Boog, PhD, International expert, EPOS

**Principal investigator:** E.Erdenechimeg, PhD, HSUM, SPH

**Coordinator:** D.Nyamkhorol, MPH, DOH

**Consultant:** L.Oyuntogos, PhD, WHO

**Researchers:**
- Ch.Tholmon, PhD, professor, HSUM, SPH
- D.Naransukh, MPH, HSUM, SPH
- S.Myagmarchuluun, MPH, HSUM, SPH
- D.Khishigtogtokh, MPH, HSUM, SPH
- Ts.Tsevegdorj, MPH, HSUM, SPH
- U.Munkhchuluun, Master student, SPH
- E.Otgonsuren, Master student SPH

**Report was written by:**
- E.Erdenechimeg, PhD, HSUM, SPH
- D.Nyamkhorol, MPH, DOH
- L.Oyuntogos, PhD, WHO

**Report was reviewed by:**
- Tatiana Grechukhina, MPH, EPOS Health Management
- Prof. Silke Graeser, PhD, International expert, EPOS Health Management
- Elena Maximenco, MPH, PhD, Team leader/Senior Public health expert, EPOS Health Management
Acknowledgements ...............................................................................................................................................6

Executive summary...........................................................................................................................................6

Abbreviations and Acronyms ...........................................................................................................................9

1. INTRODUCTION ........................................................................................................................................... 10

2. RESEARCH GOALS AND OBJECTIVES ................................................................................................. 13

3. RESEARCH METHOD AND DATA COLLECTION ..................................................................................... 15

3. STUDY RESULTS ........................................................................................................................................ 23

3.1. Diagram of health care providers who perform early cancer screening....................................................23

3.2 Female participants’ knowledge, attitudes, behavior and perceptual risk factors related with women’s CC screening .........................................................................................................................................................28

3.2.1 Screened and non-screened women’s understanding and knowledge of CC .................................................28

3.2.2 Perception, misconceptions and knowledge of CC signs and symptoms of the CC screened and non screened group of women ..............................................................................................................30

3.2.3 Perceptions, knowledge, attitude related to CC screening of screened and non-screened women.............31

3.2.4 Experiences with CC screening and referrals ..........................................................................................34

3.3 Key respondents interviews results ..........................................................................................................35

3.3.1 General information and observations ..................................................................................................35

3.3.2 Results on specific questions for key informants who perform the CC screening......................................36

3.3.3 Procedures in the CC screening process ..................................................................................................37

3.3.4 Information seeking behavior at the site of screening services ..................................................................38

3.3.5 Perceptions of key informants on knowledge and HSB of women ..............................................................39

3.3.6 Key informant’s recommendations on increasing demand for screening ..................................................40

3.4 Results of interviews with men and husbands ...........................................................................................42

3.5 Results of observation ..................................................................................................................................43

4. SUMMARY OF CONCLUSIONS ..................................................................................................................46

5. RECOMMENDATIONS .................................................................................................................................48

REFERENCES.......................................................................................................................................................51
Table of Contents

Acknowledgements 4
Executive Summary 4
List of abbreviations 6
List of tables 6

Chapter 1. Introduction 7
  • Background information 8

Chapter 2. Objectives and specific objectives 10

Chapter 3. Research methods 11
  • Study sites, sources of information and sampling techniques 12
  • Data collection techniques and tools (including pre-testing and adaptations of tools) 12
  • Data management and data quality control 17
  • Ethical considerations 17
  • Pilot study 17

Chapter 4. Study results 18

Chapter 5. Conclusions 40

Chapter 6. Recommendations 41

Annexes 44
  • References 44
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Executive summary

In 2008, 20.7% of mortality of the Mongolian population was caused by cancer, making it the second leading cause of mortality. Gender specific mortality rates were 13.45 per 10,000 males and 10.01 per 10,000 females in the same year. Women are more susceptible to dying of liver cancer (44, 23%), stomach cancer (11, 61%), esophageal cancer (9, 33%), cervical cancer (8, 04%), and lung cancer (4, 93%). The leading types of cancer in males in Mongolia are: liver (44.4%), stomach (16.9% male), lung (14.87%), esophagus (8.45% male) and prostate (2.62%)\textsuperscript{1}.

The main objective of this study was to assess cervical cancer (CC) screening development and its educational benefit among the primary level health care providers and consumers. For instance, in order to contribute to the development of informed interventions contributing to increased awareness and utilization of CC screening services at primary health care (PHC) level, it was possible to target eligible health care provider’s and selected group’s knowledge on health seeking behavior.

Research methodology: Key informants interviews, in-depth interviews, focus group discussions and observations were used for the data collection. According to the research guidelines, study participants were recruited from the two major family group practices and district hospitals which primarily screen cervical cancer (CC), as well as from the National Cancer Center. Study participants such as the above mentioned hospital’s female patients and their husbands and physicians and other health care providers were recruited to the focus group.

Study participants were 30-60 years old women who have just been screened for CC, diagnosed with CC recently through the screening program, women who already were diagnosed with CC and undergoing treatment, women who came for the screening for the first time, and awaiting

\textsuperscript{1} Governmental Agency DoH, Mongolia, Health Indicator, 2008
results in the screening room, husbands/partners of those women, physicians who have to follow up them or who have seen them and other health care providers who service them.

Purposeful sampling, quota, snowball and chain sampling were applied in the selection of study participants which include women, their husbands, key informants including physicians and nurses.

Data were gathered and filed as a compact single file in every focus group. In addition, it was reviewed several times by researchers and then listed according to their main idea, similar idea and relational ideas. Subsequently, a master page was prepared by every single focus group, and the main conception was analyzed and the result was shown.

**Research result:** Study participants such as women, men, physicians and other health care providers believe that the CC rate has increased in recent years in Mongolia and the younger generation is increasingly affected by CC. There are two major reasons that may explain why women seek gynecological care and why there are an increased number of consultations. First of all, the population’s health education improved due to physicians’ and health care provider’s cancer related information, and exposure and advertisement through telecommunication and broadcasting, and it possibly prompted an increase in the number of patients who seek gynecological care. On the other hand, the number of CC cases may have increased lately.

Women and men lack knowledge about 1) CC screening 2) how to screen in order to diagnose CC among women 3) screening benefits 4) CC causes 5) CC symptoms and 6) its prevention. Furthermore, there is an enormous need for information booklets and handouts about CC at every level of health care centers.

It is equally essential to improve women’s health seeking behavior through physicians’ and health care providers’ support, and family members’ and husband’s encouragement. Unfortunately some physicians’ communication skills and attitude toward patients affects negatively women’s health seeking behavior.

Some of the major reasons for not recruiting women’s health screening are as follows: lack of knowledge about health screening, poor health attitude particularly when people start to notice signs and symptoms, unable to get screening due to financial constraints and mostly they expect or wait for a specifically organized health screening.

The first and the second referral level health care centers are not providing cancer screenings. This may be related with health care provider’s lack of skills to screen at their level, lack of proper screening tools and equipments and lack of necessary legal regulations, at this level.

Based on the study results recommendations may be provided that can help to formulate a policy on how to screen CC cost-effectively, efficiently and equitably, develop tools that increase
population’s health education on CC and develop CC early detecting services by improving human resources’ professional skills.
Abbreviations and Acronyms

BCSG-        Breast Cancer Screened group
CC –         Cervical cancer
CC -         Screened Group - Women who have been treated with CC, women who have gone through CC screening and women who have gone through the screening and waiting laboratory findings for further diagnosis
FGD –        Focus Group Discussion
ICE –        Information, Communication and Education
HSU-         Health Science University
KAP –        Knowledge, Attitude and Practice
MCA –        Millennium Challenge Account
NCC -        National Cancer Center
NCDI –       Non-Communicable Disease and Injuries
Non-Screened Group - Women who come for the first time for CC screening
PH-          Public Health
PHC -        Primary Health Care
RDTC -       Regional Diagnostic and Treatment Center
RAS -        Rapid Assessment Study
SPH-         School of Public Health
UB-          Ulaanbaatar

List of Tables

Table 1. Study participants
Table 2. Health care service referral level of CC patients

List of figures

Figure 1. Early detection, early diagnostic and referral flow chart of CC
Figure 2. CC treatment
1. INTRODUCTION

Health Priorities

Globally, non-communicable diseases (NCDs) such as cardiovascular disease (CVD), adult-onset diabetes (type II), cancer and chronic respiratory disease account for more than half of all deaths. The tragedy is that these diseases cause many to die too young from conditions that could have been prevented or controlled if detected early and treated properly. Injuries represent 12% of the global burden of disease and are the major cause of death among 15 to 40 year olds. More than half the people killed in traffic accidents are young adults between 15 and 44 years old.

Mongolia, too, is experiencing a high burden of non-communicable disease and injuries (NCDIs) within the working age population (15–60) due to rapid urbanization, other lifestyle changes and an inadequate national response. This has a serious negative impact on family well-being and the productivity of the labor force.

MCA-Mongolia NCDI Project

The Government of Mongolia asked the Millennium Challenge Corporation (MCC) of United States to support the national strategy for preventing and controlling NCDIs. With MCC support, a five year health project was launched in September 2008 under the direction of Millennium Challenge Account-Mongolia (MCA-Mongolia). The project is managed by the Health Project Implementation Unit (PIU). The project’s long term objective is to increase the productive lives of Mongolians. The project’s more short term objective is to increase access to information and services about NCDIs, which will enable Mongolians to guard their health.

The project focuses on the four major NCDs and road traffic injuries, which are among the major causes of premature adult death and disability in Mongolia, and, which can be prevented and/or successfully treated. The four NCDs are hypertension, adult-onset diabetes (type II) and breast and cervical cancer. The target population is the working age adults. Working with national and local government, private and voluntary institutions including national level non-governmental organizations (NGOs), citizen and community groups, universities and private enterprise, the project seeks to strengthen the national and individual response to NCDI.

Focusing at the primary health care level, the project is supporting activities which promote behavior change and other risk reduction actions, the early detection and treatment of the four diseases, greater prevention and improved response to road traffic accidents and other public and private responses to NCDI which enable citizens to adopt healthy life styles and take increased responsibility for their own health. The intention is to support evidence-based, cost-effective
interventions at the primary and secondary health care levels that can be sustained after the project ends in September 2013.

To provide decision makers and program implementers with information on the most effective, affordable and sustainable approaches to these major NCDIs, the project is also supporting short term applied research and special case studies.

**Current State of Affairs**

To date few studies have been conducted in Mongolia focusing on the demand for cervical and breast cancer screening. This Health Seeking Behavior Research is aimed at a better understanding of the underlying interconnected causes for the variations in uptake of cervical and breast cancer screening among female populations respectively between 35 to 60 years. According to data from the DOH in 2007 the prevalence of breast cancer was 5.6; the prevalence of cervical cancer in Mongolia was 59.5. Out of these women 80% came too late to the health care center. The Mongolian Government has adapted a sub-programme on cancer prevention which includes a WHO policy on cervical cancer screening.

On breast and cervical cancer a KAP survey was undertaken by the MOH/RH department in 2008 in selected areas in Mongolia (UB included). Regarding cervical cancer the KAP survey undertaken by DOH revealed that knowledge on cervical cancer was very low among all age groups. The lowest level of knowledge was found among the youth aged 15 to 19 years. Knowledge on cervical cancer increased by age and older women were more likely to have heard about cervical cancer. However, a perception of the need for screening is absent and is the main reason for not going or having been screened.

**Background**

Mongolia is experiencing a high burden of non-communicable diseases and injuries (NCDIs) particularly, cardiovascular diseases, diabetes, cancers and injury-induced trauma. A five year technical support plan has been approved and aims at strengthening the Mongolian National Program on Prevention and Control of NCDs. The outcomes of the NCDI project should be as follows:

- Increased awareness of NCDI risk factors;
- Early detection and
- Increased access to efficient interventions

One out of five immediate NCDI project’s objectives is defined as:

Promote prevention, early detection and appropriate treatment of cervical and breast cancer. The project includes 4 phases. The first phase is ongoing and aims at gathering information on the basis of which priorities and strategies can be developed to lead to the expected outcomes of the
NCDI project and thus the National NCD program. The present research is part of the broader Rapid Needs Assessment (RNA) to be completed in the first phase. It will be one out of several priority studies.

**Current cancer situation in Mongolia**

In 2008, 20.7% of mortality of the Mongolian population was caused by cancer, making it the second leading cause of mortality. Gender specific mortality rates were 13.45 per 10,000 males and 10.01 per 10,000 females in the same year. Women are more susceptible to dying of liver cancer (44.23%), stomach cancer (11.61%), esophageal cancer (9.33%), cervical cancer (8.04%), and lung cancer (4.93%). The leading types of cancer in males in Mongolia are: liver (44.4%), stomach (16.9% male), lung (14.87%), esophagus (8.45% male) and prostate (2.62%).

73.4% of those who were diagnosed with cancer seek health care service at the third or fourth stage of cancer and 44.2% of cancer sufferers die within one year after the initial diagnosis. 88% of all CC cases were diagnosed at the second stage or later stage of the illness. This is due to a lack of knowledge about CC treatment options in the early stages, lack of knowledge about CC early signs and symptoms and lack of health care service access at the first referral level hospitals in rural areas (Sub-program on Cancer prevention and control, NCC, 2008).

A Sub-Programme on Prevention and Control of NCDs was approved in 2008 by the Minister of Health’s decree number # 246. The Sub-Programme includes activities aiming at the reduction morbidity and mortality of all cancers especially breast and cervical cancer, reducing risk factors for breast and cervical cancer, making the diagnosis and treatment of pre-cancer diseases, increasing accessibility and affordability of health care, and increasing the quality and access to screening facilities. In 2006, the five years survival rate of BC after the initial diagnosis was 32.4%, in 2009, it was 28.2% and by 2013 it is expected to be 31% (Sub-Programme on Cancer Prevention and Control, 2008).

The MCA a funded project on prevention and control of the major NCD in Mongolia has the goal to contribute to the reduction of mortality and morbidity of breast and cervical cancer. In the scale of the project there is a need to explore health seeking behavior (HSB) with respect to screening of breast and cervical cancer in selected areas of Ulaanbaatar (UB) and to develop targeted intervention programs.

**Rationale of the study**

“Specific diseases and public health problems identified for emphasis under this Project include primary health care (PHC) and public health interventions for cardiovascular diseases (CVD),

\[\text{Governmental Agency DoH, Mongolia, Health Indicator, 2008}\]
adult on-set diabetes (Type II), breast and cervical cancer, hypertension, smoking and drinking amongst youth, and injuries related to road traffic accidents” (Project documents of the MCA funded project).

A KAP survey on breast and cervical cancer screening has been undertaken by the Ministry of Health; however, a qualitative study in Mongolia focusing on the demand for breast and cervical cancer screening services has never been undertaken. In a participatory way, the project agreed on designing a qualitative study on HSB related to breast and cancer screening. The draft research protocol has been developed by national and international experts and the study has been approved by the Scientific Committee of PHI at Mongolian Health Science University on the 14th of October 2009.

Due to the fact that breast and cervical cancer are different types of cancers from a bio-medical perception and more important from a “lay” person’s point of view, it was decided to develop two research designs: one on HSB with respect to breast cancer (BC) screening and one on HSB with respect to cervical cancer (CC) screening. Both BC and CC HSB studies will utilize qualitative methodologies to obtain a first insight in the underlying and interconnected causes for the variations in the uptake of cancer screening.

2. RESEARCH GOALS AND OBJECTIVES

Goal of the study:

To explore and describe perceptions and HSB related to CC and the responsiveness of staff in public CC screening services in UB in order to contribute to the development of informed interventions contributing to increased awareness and utilization of CC screening services at PHC level. Indirectly it is related to the availability and accessibility of the screening.

Main objectives:

1. To identify factors influencing HSB related to CC screening among women having gone through and/or are about to use CC screening services;

2. To explore public health care provider’s understanding and attitudes related to perceptions and HSB of women having gone through and/or are about to use CC screening facilities;

3. To identify state health care providers’ perspectives on appropriateness of CC screening services offered.
Additional objectives:

1. To explore males’ thoughts and believes about CC screening and its use by their wives and/or female family members;

2. To explore men’s influences on wife/partner’s actual utilization of CC screening services;

3. To make inventories of potential interventions (suggestions) targeted at women, families, communities and health care providers aimed at increasing the awareness and utilization of CC screening services;

4. To contribute to forthcoming studies on CC screening.
3. RESEARCH METHOD AND DATA COLLECTION

Research Method

Due to the limited information resources on motives of women to make decisions whether to have or not to have CC screening, the present study utilized an exploratory (and partly descriptive) method of information collection.

The topic-guide consisted of the following questions:

- what interviewers know about CC screening,
- what beliefs they have about CC,
- how women make decisions whether they should go or not to undergo CC screening based on these set of beliefs,
- what way women will accept positively CC screening
- what factors could influence decisions they make for CC screening.

The present study utilized a Rapid Assessment Study (RAS) method that was limited to selected areas in UB. Therefore, the study results have shown the perceptions and behaviors of respondents and key informants such as women who have gone through or about to go through CC screening in UB, women who referred or about to be referred from countryside to CC screening and UB based state health care providers including physicians, nurses and other health care professionals.

The reasons for RAS use are as follows:

- cost effective and easy to complete in a short period of time;
- pragmatic approach (collect data leading to the most optimal information needed for answering the research questions fulfilling the objectives);
- use of multiple sources of information and range of research techniques (multi-indicator approach which facilitates the process of triangulation);
- inclusion of both need and resource assessment (demand and services);
- easy to assess what is happening and why it is happening.
**Action oriented approach**

The research results will be used for the development of programmes. For instance, certain results will be taken into consideration in the development of potential interventions, which should be culturally, socially, economically and politically appropriate for the particular population. Also, it can assist the particular way to adopt individual’s health seeking behaviors among women who wish to go for CC screening.

**Demand and supply side**

The study focused on both the demand and supply side of the CC screening in UB. Patients and providers were of the public screening and treatment services. For example, state health care providers who screen and treat CC cases and screened women and their husbands/partners were recruited in the study.

**Data Collection Method**

The data was obtained by investigating different resource materials such as secondary research materials and publications and through multiple research techniques.

**Pre- data collection phase:**

During pre-data collection phase we reviewed available research related literature and information (see Manual) which were the secondary research materials, journal publications and official sites primarily about CC screening. In addition, we revealed a current mapping of CC early detection services in particular in community locations.

**Data collection phase**

Field data collection methodologies were as follows:

- In-depth interviews
- Key informants interviews
- Focus Group Discussions (FGDs)
- Semi-structured interviews (with men)
- Observation
- Community meetings
- Informal meetings
The following research triangulation was utilized but we used more than one triangulation rule in this study.

- Data triangulation: to utilize various information resources
- Investigator’s triangulation: to organize multi-discipline team members
- Methodological triangulation: use of multiple study methods e.g. observation/in-depth interview/case studies/FGDs and interviewing key informants.

**Selection of the study sites**

According to the research guideline, study participants were registered from the two major family group practices in UB and district hospitals – facilities that primarily do CC screening, and from the National Cancer Center.

The study population was recruited from the following sites.

- National Cancer Center
- District Hospitals
- Family Group Practices

**Focus groups and in-depth interviews**

Study participants were 30-60 years old women who met the following criteria:

- Women who have been treated for CC, women who have gone through CC screening and women who have gone through the screening and waiting for laboratory findings for further diagnosis were classified as CC screened group.
- Women who came for CC screening for the first time and waiting outside of the physician’s office were considered as non-screened group.

Separate focus groups discussions have been organized for the participants of these groups.

In-depth interviews were organized with participants of CC screened group and non-screened group regarding their history of illness. A detailed report was filled in every single case. Interviewers were trained for data collection specifically for taking interviews and facilitating focus group discussions.
Health care providers were included in the key informants’ interviews. Semi-structured interviews among key informants were held in two different subgroup’s interviews such as identical professional and variable different professional group according to their accountability and professional responsibility of the CC screening.

Furthermore, separate subgroup interviews were conducted among CC screened group and non-screened group of women. In addition, separate focus group interviews were held among physicians and nurses.

Husbands/partners of women were recruited for semi-structured individual in-depth interviews. Male researchers who had specified interview training interviewed these men.

**Sampling techniques**

In order to study participant’s health seeking behavior the purposeful sampling technique was utilized. One of the key elements of this CC research was to select information-rich respondents (women and health professionals). Within the framework of purposeful sampling, quota and chain sampling methods were applied.

The latter approach was to locate information rich individuals through other individuals involved in the research and utilizing this kind of approach was a main method of participants’ selection. (E.g. who knows a lot about the topic under investigation and whom should I talk to?). During the study period the researchers discussed prior to the research who might know better about the topic and who could be invited in the selected hospitals. Subsequently, key informants were identified and invited for the interview.

In order to choose the study participants among women, purposeful sampling technique were utilized and researchers planned to invite the women who came for the first time for CC screening, women who are diagnosed with CC through CC screening, waiting for the test result and undergoing treatment.

**Research tools**

Individual in-depth, key informant’s interviews, focus group discussions and observation techniques were used in the study; relevant literature review was also used for the purpose of the study.

**In-depth interview for female participants:** In-depth interview questions were developed in five different ways among the CC screened group and in three different ways among the not screened group of participants.
Not screened group of participants’ questions:
- CC perception and knowledge of the disease
- Perception, misconception, and knowledge of symptoms of CC
- Attitude and referral experience before CC screening

CC screened group of participants’ questions:
- CC perception and knowledge of the disease
- Perception, misconception, and knowledge of symptoms of CC
- Attitude and referral experience before CC screening
- Expectations on the CC screening service
- Attitude and referral experience after CC screening

Key informants interviews:
Key informants were interviewed in order to explore health care provider’s understanding, and attitudes related to perceptions and health seeking behavior of women and to identify health care providers’ perspectives on appropriateness of CC screening services offered. The following questions in detail were used for key informants interviews.

- General information and observational questions
- Specific questions for physicians and other health care providers who screen CC
- Women’s behavior during the screening service
- CC screening process steps (from inviting women to communicating the result)
- CC screened group and not screened group’s health seeking behavior and perception
- Key informants’ recommendation on how to improve the screening service.

Focus group interview:
All FGDs are aimed at contributing to the same objectives as the in-depth and key informants’ interviews. Therefore, a limited number of topics out of the above mentioned interview were selected as the focus for the FGDs. The topic-guide is attached to the report. FGDs were composed of participants of the same occupation (nurses), same sex and working at the same
service/organization (homogeneous group) and different occupations (nurses/doctors/health education specialists).

**Husbands or male participant’s in-depth interview:** Male in-depth interviews were conducted to explore husband or men’s perception, willingness to understand, knowledge and attitude towards CC screening, CC causes and wife or women’s complaints and symptoms.

**Observation:**
Observations were made in the waiting rooms of screening services and in the examination rooms of family group practices, district hospitals and the NCC. Daily observations were conducted during work days and lasted up to six hours during the OBGY exams and laboratory tests.

Observation is one of the most essential parts of qualitative information resources and during the first observation in waiting rooms of screening service information can be collected directly. The study observer was trained specifically for recording current action, collecting detailed and objective information in waiting and exam rooms.

Observation guidelines included the following:

- To describe the physical environment of a particular hospital without an evaluative statement such as crowded etc
- To observe whether women in the waiting room talk to each other and if they talk on what kind of subjects
- Are there posters, pamphlets, booklets on cancer screening and its treatment available in the waiting room?
- Are pamphlets, booklets used by the women in the waiting room?
- How women are invited to the screening room
- How much time (how many minutes) do they spend in the waiting room in order to get a screening
- Do women take appointments?
- Do they have a dressing room for women?
- Do they have a ladies room?

**Community meetings and non-official meetings:** Community meetings were held during the research methodology training, research data collection and during data analysis. Non-official meetings were organized as a discussion panel among oncologists, health support specialists and the NCD project and program staff.
### Research coverage

Table 1. A number of in-depth interviews and FG discussions

<table>
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<tr>
<th>Study sites</th>
<th>Number of participants and rate of focus group interviews</th>
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<tbody>
<tr>
<td></td>
<td>Female respondents</td>
</tr>
<tr>
<td></td>
<td>Key informants</td>
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<tr>
<td></td>
<td>Husbands/male participants</td>
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| **National Cancer Centre** | In-depth interview  
CC screened women - 12  
Non CC screened women - 9                                                                 |
|                   | Focus group interview  
CC screened women – 2 groups (12)  
Non CC screened women - 2 groups (12)                                                                 |
|                   | In-depth interview  
Physicians - 3  
Nurses - 4                                                                 |
|                   | Focus group interview  
Same group - 1 group (6)  
Different group- 1 group (6)                                                                 |
|                   | Husband/male participants - 6                                                                                             |
| **District hospitals** | In-depth interview  
CC screened women - 2  
Non CC screened women - 9                                                                 |
|                   | Focus group interview  
CC screened women – 1 group (7)  
Non CC screened women – 1 group (8)                                                                 |
|                   | In-depth interview  
Physicians - 3  
Nurses - 2                                                                 |
|                   | Focus group interview  
Same group - 1 group (5)  
Different group- 1 group (6)                                                                 |
|                   | Husband/male participants - 3                                                                                             |
| **Family Group Practice** | In-depth interview  
CC screened women - 4 interviews  
Non CC screened women - 4 interviews                                                                 |
|                   | Focus group interview  
CC screened women – 1 group (3)  
Non CC screened women – 1 group (6)                                                                 |
|                   | In-depth interview  
Physicians - 2  
Nurses - 2                                                                 |
|                   | Focus group interview  
Same group - 1 group (4)  
Different group – 1 group (4)                                                                 |
|                   | Husband/male participants – 3                                                                                             |
Data management and data quality control

One day training was organized at the Conference Hall of PHI of MHSU February 1st, 2010 for researchers and research teams. In total, there were four research teams consisting of two members each that participated at one day training session.

According to the research protocol, only female researchers could interview female participants due to the sensitivity of the subject and male researchers could interview male participants. The researchers proposed a data collection schedule and planned to interview four to five female participants and conduct one FGD per day.

Each research team included a team leader and a secretary. At the end of each day sessions, the team leader was responsible of converting the interviews and the data that was recorded on a tape to a digital text format. The project manager was responsible for collecting all research related data.

An official letter that explains the study purpose, conception and its benefits was sent out to the selected sites such as family practice groups, district hospitals and NCC’s administration and officers before the study. In addition, it was kindly requested from the facilities to provide in-depth and focus group interview rooms, to plan an interview schedule for the focus groups, to list key informants’ name lists and to support all the arrangements that need to be done before the actual study starts.

Pilot study

Pilot data collection was held at the NCC, in order to determine how well the study interview questions correlate with the current situation, female and male participants, key informants’ perception of the study, and to determine convenience of the given timeframe of each session. In this study 3 female participant’s groups, 2 male participant’s group and 2 key informant’s groups were interviewed. Moreover, focus group interviews were organized among physicians and nurses. As a result of a research pilot, analyses of the interview guidelines and its concepts were completed and the necessary amendments were made to finalize the study proposal.

Ethical consideration

The research obtained permission from the Ethical Committee of the Ministry of Health on March 5th, 2010 based on an ethical research methodology and research permission consent form. A signed consent form from all respondents was obtained prior to their participation in the study.
Data processing and analysis

According to the proposed data collection tools in the qualitative research manual, topics of the interview tools are grouped according to headings. Subsequently data were transcribed and coded and categorized. Three researchers edited headings at the same time and filed them by each focus group. After the filing data was subjected to reading and re-reading with a view to identifying patterns, similar phrases, relationships between sub-groups of data and common sequences.

3. STUDY RESULTS

3.1. Diagram of health care providers who perform early cancer screening

According to the cancer prevention and control sub-program, CC patient’s referral for screening, diagnostic work-up and treatment should be according to the following diagram:

*RDC are serving in Khovd (for 410624 population), Uvurkhangai (for 435643 population), Dornod province (for 193511 population) and in Ulaanbaatar (for 1.195763 population) as today.

Cancer prevention and control sub-program stated that the patient who was diagnosed with cancer in their late stage can have false hope as referral continues up to third level referral hospitals and its psychological and economic costs can be enormous for health care and patients. Therefore, it is critical to improve the cost effectiveness for cancer cases, to improve treatable cancer cases referral to NCC at the right stage and to improve isolated IDTC’s cancer service and sustain their capacity (Sub-program on Cancer prevention and control 2008).
A current screening, diagnostic and treatment capacity of cancer in the above mentioned health organizations were determined in 2008 as follows:

**NCC Pathology laboratory**
- Cytology test
- Mammography screening
- Laboratory
- Radiation therapy
- Surgical treatment
- CT

**RDTC**
- Mammography
- Cytology test
- Colposcopy
- Pap smear
- Ultrasonography
- X ray
- Laboratory

**First and second referral hospitals**

Palliative treatment should be provided for first, second, third and fourth stage of cancer patients particularly “to communicate bad news”, pain management, symptomatic treatment, follow up and home treatment by the first and the second referral hospitals.

The cancer prevention and control sub-program stated that health care providers who work at the first referral hospitals especially village or town physicians, family group practitioners and midwives should be trained in performing acetic acid test and perform acetic acid test for all women from 30 to 60 years old every three years. If the test results are positive then local physicians and midwives are instructed to refer them to province and district hospitals for further diagnostic work-up. But family group practice hospitals and district hospitals that were recruited in our study were not able to perform such acetic acid tests.
Adopting health seeking behavior among women who live in rural areas can be challenging due to the following factors: lack of human recourse capacity to provide cancer care service at the first referral hospitals in the rural areas and lack of necessary tools and equipments to screen CC. Because of these factors it is difficult to embed a habit of undergoing preventive screenings at the RDTC and NCC without any noticeable symptoms to the women in the rural areas. For above mentioned reasons there is an urgent need to formulate mandatory and voluntary screening policies (social requirement) that might help to encourage health seeking behavior among women. Furthermore, it is equally important to maintain accessible, qualified, cost-effective and time efficient screening environment.

In the CC diagnostic and treatment standard coded as MNS 5855-2:2008 CC determination, classification, risk factors, path-physiology, clinical signs, diagnosis, differential diagnosis, treatment and complications after the treatment are specified. Regardless of property kind, all types of health care organization’s health care providers that provide surgical care and services under the Mongolian Health law should follow this standard for their daily services.

The CC diagnostic and treatment standard coded as MNS 5855-2:2008 as shown in Table 2 specifies CC services and laboratory test at each referral level.

<table>
<thead>
<tr>
<th>First health care referral service</th>
<th>Second health care referral service</th>
<th>Third health care referral service</th>
</tr>
</thead>
<tbody>
<tr>
<td>- To take history of illness and examine CC patients and to refer them to specialized physician</td>
<td>- To receive specialized physicians (e.g. OBGY and OBGY oncologist) at the second referral hospitals</td>
<td>- To take history of illness, to perform complete OBGY exam and conclude CC diagnosis and stages.</td>
</tr>
<tr>
<td>- To conduct treatment for CC patients according to higher referral hospital’s recommendations</td>
<td>- To take history of illness, to examine complete OBGY exam and to make diagnosis</td>
<td>- In order to confirm their diagnosis the following tests are available at the third referral hospital:</td>
</tr>
<tr>
<td>- If they diagnose CC in late stage they should not refer patient to higher referral hospitals rather to treat patient’s signs and to perform palliative or hospice care</td>
<td>- To perform further diagnostic tests as follows: o Complete blood test o Urine test o Biochemical test o X-ray of lower abdomen o ECG o Chest X-ray (film or</td>
<td>o Cytology findings o Biopsy o Contrast excretion urogramm o Cystoscopy and colonoscopy o Lower abdominal X-ray o CT o MRI</td>
</tr>
<tr>
<td>- To consult patient and their family on how to care CC patients at home</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The cancer diagnostic and treatment standard states that cytology and biopsy tests for the early CC screening are only available at the third referral level hospitals especially at the NCC; therefore, only one hospital has the capacity to conduct CC screening according to the standard. Therefore, the NCC is overloaded by patients. On the other hand, according to the standard patients always have to have a referral report A13 that confirms they have gone through the first and the second referral hospitals in order to get service at the third referral hospital.

Additionally, the standard demonstrates five different standard treatments (as shown below in Graph 1) for pre-cancer illnesses and CC based on cancer staged.
Graph 1. CC exam and treatment

**OGBY EXAM AND CYTOLOGY TEST**

- **Normal findings**
  - Next diagnostic step
  - Pre-cancerous illnesses
    - CINI
      - Repeat cytology test and follow up
        - If the change is stable coagulation treatment
  - Cancer suspicion
    - Colposcopy, biopsy and pap smear
      - CIN II
        - To cut down by coagulation or conization
          - If patient is over 50 y.o complete amputation of uterus
      - CIN III
        - To cut down by coagulation
        - If patient is over 50 y.o complete amputation of uterus
      - Micromalignant cancer
        - (Ia) Malignancy is less than 1 mm
        - Conization and if patient is over 50 y.o complete amputation of uterus
        - Malignancy is 2-3 mm complete amputation of uterus
      - 5mm malignancy(Ib)
        - 1. Extended surgery of complete amputation of uterus
        - 2. Radiation therapy
        - 3. Chemotherapy

- Observation, cytology follow up and physical therapy
The CC diagnostic and treatment standard does not determine early diagnostic screening methods, its frequency and where the early diagnostic screening should held. Moreover, there is no other specific standard that regulates the above mentioned issues.

The health indications published from the MOH, The Governmental Implementing Agency, Department of Health does not include any information about the coverage of the CC screening services, CC screening coverage, current CC screening state and CC screening recruitments due to lack of central registering and reporting system.

Qualitative research findings

3.2 Female participants’ knowledge, attitudes, behavior and perceptonal risk factors related with women’s CC screening

3.2.1 Screened and non-screened women’s understanding and knowledge of CC

Both groups of women responded that the number of women who visit the NCC, district hospital’s cancer department, has been increasing as well as the number of women who seek diagnostic and treatment care in private OBGY hospitals. They responded that they heard that women at younger age are affected by cancer. Some of them noted that they heard about the abrupt increase of cancer morbidity in Ulaanbaatar as well as in the countryside.

In some cases, women were able to receive information from daily newspapers, publications, particularly specialized physicians’ interviews in media and the internet.

It was more often reported to be exposed to CC related information when study participants had siblings, relatives, acquaintances and family members with CC. Most of them were aware that their family members, siblings, relatives and acquaintances applied to health care too late after explicit symptoms. Particularly, women who are from the rural areas found out about their illnesses at a late stage and visit the third referral hospital for the final diagnosis due to the local diagnostic incapacity. For some instances women believe cancer can be inheritable.

Case 1
One of my relatives came from the countryside and had a surgical treatment for cancer. I visited her a year ago and she was completely fine and healthy at that
time. Unfortunately she was diagnosed with cancer in less than one year so I think the cancer can spread so easily and so quickly.

Case 2
My friend’s mother was diagnosed with cancer and died before the New Year holiday. The district hospital physicians were not able to diagnose her correctly; therefore, she wasted much of her time at this referral hospital. They recommended that it should be cured and I should start the treatment on a timely manner.

The CC is a treatable health problem and patients with CC can have surgical, radiation and chemo-therapy in UB. In private clinics CC diagnosis and treatments are fairly expensive but in a government hospital the CC treatment is free if you have a health insurance.

Women who have not been screened for CC, in majority believe that CC treatments are limited only to surgical treatments.

Case3
People have a lack of knowledge about CC negative impacts. Also they do not follow physicians’ recommendations; therefore, CC can complicate easily. Lack of access for health care providers recommendations and after treatment nursing care are often occurring problems. Especially, it is true for women who are from the countryside because after the hospital discharge they tend to stay in some relative’s or friend’s house. Because of such inconvenience they tend to return to their home without completing their treatments. It is very complicated for country people like us to be sick in UB.

The family group practices and district hospitals do not provide CC treatment. Only the NCC and a limited number of private clinics treat CC patients. The difference between the private and the government clinics is the quality of care. For example, focus group participants agree that government hospitals provide better quality care than the private ones. Thus, according to the study results the patients who had a treatment at the NCC have much higher satisfaction with their treatment results, with less after treatment complications compared to women who had treatment in private clinics.

Most of the study participants expressed their anxiousness in the beginning due to lack of information on the effectiveness of the treatment and they were not confident in the effectiveness of the treatment. Therefore, lack of information and confidence about CC complete remission and healing was one of the main causes for women to refuse CC treatment. On the other hand, financial incapacity for rural people and disregard for personal health was also one of the main reasons not getting a CC treatment.
Women who had CC screenings expressed that they can openly discuss about CC in contrast to women who did not have CC screenings.

The knowledge gap between the participants from the city and countryside regarding CC was quite considerable. For instance: city women believed that causes of CC are being not faithful to each other as a couple, having multiple sex partners, early age sexual relationship, abortions, sexually transmitted diseases, and husband’s education level. On the other hand, country women believed that CC causes are smoking, heavy drinking, complicated delivery, chronic illnesses and stress.

Although some women know that CC is a completely preventable disease and in order to prevent CC it is essential to have early diagnostic work-up, treatment, better self care, being faithful to each other and do annual preventive screening exam. Unfortunately, there were women who did not know about such basic preventive measures.

CC patients are often encouraged by family members, friends and physicians and other health care providers but husband’s and family member’s encouragement is most important for women. Moreover, physicians’ and other health care provider’s especial attention and encouragement are vital.

Case 4
Physicians are kind to us but it often depends on the person. Some physicians criticize us why we come in this late. If physicians encourage us treatment seems more effective. The most encouraging people are health care providers. If they are very nice and kind, the patients will be able to get information easily.

All participants in the CC screened group and in the non CC screened group answered that the first person to tell about their health condition will be their husbands. Also, they answered that it is embarrassing to tell about such health problems to their friends and relatives because they will not understand their situation as well as their close family members.

Women consider that men/children do not have enough knowledge about CC; therefore, they believe it is not necessary to discuss CC related issues with them.

3.2.2 Perception, misconceptions and knowledge of CC signs and symptoms of the CC screened and non screened group of women
When women from the CC screened group started to notice signs and symptoms of pain they immediately were seeking medical attention. Signs and symptoms vary. For example: abdominal and back pain, abdominal enlargement, pain at the location of ovaries and bladder, increased discharge, and heavy bleeding. Before seeking medical care most women talked about their health related discomfort with their husband and family members.

A majority of women who have CC before seeking hospital care were not able to receive treatment at home and in one case due to poor knowledge about CC symptoms, a woman had an antibiotic treatment because she assumed her symptoms were for kidney and bladder inflammation as a self treatment.

It has been reported that in most cases women share their symptoms with their husbands and the husbands recommend seeking health care. Also, in most cases, women answered that it is emotionally tough to share such problems with their husbands and they tend to cry during such conversations.

Before seeking care there was lack of information about “abnormal signs and symptoms” of CC among both women from the city and countryside. And women in CC screened group did not have knowledge about how to prevent from “abnormal signs and symptoms” or they seem that they had a misconception about “abnormal signs and symptoms” in general. After the screening they had much more information. The unscreened group of women still does not have proper and right information about signs and symptoms of CC.

Case 5
It is hard to predict and all of a sudden I had this disease. I just cannot understand why I have this disease and what caused it...

3.2.3 Perceptions, knowledge, attitude related to CC screening of screened and non-screened women

Women from urban areas think that it is easier to seek health care services from private clinics due to its easy access despite its expenses rather than seek care from family practice groups and district hospitals. In contrary, for women from the countryside it is common to go to town or village hospitals and province hospitals.

Case 6
When we get sick we will visit our town or village physicians first. The town or village physician will tell what to do how to proceed further. This time the doctor referred me to this hospital. People from the countryside seek care from the local
hospitals first. Sometimes local hospitals are not qualified; therefore, country people visit the third referral hospitals.

Case 7
I came with my husband from Bulgan province because I was having a pain in the right lower part of the abdomen. Bulgan province hospital referred us to the third referral hospital in UB. The province hospital is much closer than the town or village hospital and the care is free. So we visited to the province hospital directly. I compared my complaints with a healthy person and I thought the signs and symptoms were abnormal. Our village physician seldom visits local families and during their visits they distribute brochures that explain risks and factors of cold, AIDS, drinking and smoking.

The majority of non CC screened women never heard about CC screening services and they seek care when they realized that they are having abnormal signs and symptoms. During their visit to the family group practice, town hospitals and district hospitals they usually acquire information about CC screening services.

All women answered “yes” to the question whether they would undergo screening if they would notice any abnormal signs and symptoms. However, they prefer to be alone on their first visits. If there were no noticeable symptoms of CC, the motivation for voluntary CC screening was low.

Case 8
Sure we will visit. If we had access to CC diagnostic and treatment care in our local hospital it would have been very convenient for us. We can undergo screenings independently, because in Ulaanbaatar we require our relative’s assistance in order to get around the city and to assist us communicate effectively with the doctors.

It is beneficial for the population when physicians and specialists inform the population through mass media about CC causes, clinical signs and symptoms, CC treatments, treatment complications, its negative effects and where to seek care when they have abnormal signs and symptoms.

Case 9
Finally now I have some understanding after coming to third referral hospital. In countryside, we need much more information about cancer, for us as well as for the physicians. When I came to the third referral hospital I thought I had cancer. But for the final diagnosis, I have to have more detailed diagnostic work-up. Therefore, I wish I could have better understanding about what exactly CC is and
what kind of diagnostic tests confirm the final diagnosis. I prefer to receive CC information from health care providers.

Case10

Men should not stay behind from all important parts of life. In recent years men education level significantly decreased in contrast to women, in our country. They will be husbands and fathers of children in the future. For this reason, although they do not have the exact same organs like ovaries and uterus as women they still need to know when their mother, wife and daughter needs to seek care and they should encourage them to visit CC screening.

Some women answered that there are no reasons for them not to undergo screenings but most women answered that they can hardly find time for screenings since they were too busy with their household burdens and responsibilities.

Women in the non screened group described their reasons for not undergoing screening as: no evident abnormal signs and symptoms, lack of information, lack of time, irresponsibility. Women from the countryside also named being far from health care services, poor attitude from the physician’s side.

Case11

In the countryside most people are busy managing their livestock; therefore, it is complicated for us to visit local hospitals frequently. We only seek care when we get sick. There is a common misconception among people in the countryside that hospitals are solely for treatment and care and preventive visits may seem very awkward here.

People lack information about CC screenings and health care providers including physicians never provide information about CC prevention.

Case12

I don’t know about CC screening. I think Pap smear is a preventive screening. Probably it is slightly painful. I heard before if there is a change biopsy should be done; therefore, it can be slightly painful. It is important for ordinary people to know how they perform biopsy and other tests for CC because we have no idea how they perform the procedure and it is scary.
3.2.4 Experiences with CC screening and referrals

Although CC screened group women have been seeking care initially from family group practices, district and town hospitals they preferred to visit the second and third referral hospitals including NCC, province hospitals and other private clinics for the final diagnosis.

Participants said that the waiting room for screening services is crowded, inconvenient and lacks information pamphlets, booklets and posters about CC. Some women informed that there were information board and posters on the wall but they were not able to tell how useful it was for them.

Higher rate visits were registered among women aged over 35 in the NCC and district hospitals. Particularly, there was a large number of women visiting the NCC for the confirmation of the diagnosis.

Most women from UB expressed that they were accompanied by their husbands and their husbands took active roles in the decision making process as well as in providing moral support. On the contrary, women from countryside mostly visited to the third referral hospitals alone or with some relatives who can guide them around.

The study participants wanted to ask about CC screening process from their physicians but they feared that doctors would criticize them for coming at this late stage. On the other hand, they said that doctors are usually busy and it is very hard to communicate with them due to their bad attitude. It should be noted that physicians never explain about screening process rather they talk about treatment and treatment related recommendations. Conversely, women never ask about early preventive screening they rather ask general treatment questions like whether their condition is treatable or not, what kind of treatment can be beneficial and why they are having pain etc.

A certain group of women was able to discuss openly with other women who were also present in the waiting room their experiences, cancer clinical signs and symptoms, previous hospital visits and the kind of treatment they had before. The majority of women answered that there is no information about CC screening in the waiting room area so they just wait for their appointment. Nevertheless, only one woman answered that there were CC information materials in the waiting room area but it was too late for her.

During the CC screening certain nurses and physicians were kind but not all of them are nice and understanding. They never explain the diagnostic tests process and physicians give advice only after the exam.
Most women had fear about the diagnostic test results whether it is cancer or not, whether it is treatable or not and whether it will be surgical treatment or not etc. Most women shared the test result with their husbands and husbands are often showing concern and provide moral support.

The study participants responded that they believe CC screening is helpful to diagnose CC at an early stage and it allows patients to prompt treatment actions and avoid cancer complications. Health care providers provide enough information about patient’s next follow up visits and treatment. So, there is absolutely no reason for not coming again and to postpone their follow up visits.

*Case13*

- If I get sick again I will come back to the hospital...
- Physician recommended that I need to come for an annual checkup. But he did not mention where I should go. Probably here at this hospital (Countryside).

### 3.3 Key respondents interviews results

#### 3.3.1 General information and observations

Key informants responded that in the last two years, there has been a significant increase in the number of women who are screened for CC. Gynecologists of the National Cancer Center said that almost half of the total number visits were diagnosed with pelvic inflammatory disease, pre-cancerous diseases and cervical cancer. They said that this is due to a recent advertisement about CC through the mass media women’s health education and self care improved; therefore, the numbers of women who seek proper care have increased significantly. The women have been saying that recently most of TV shows the programmes on health education and advertisement of the private clinics and doctors, not only about cancer, it covers all health issues. On the other hand, a rapid increase in number of reported cases of STI’s is also a major risk factor. But some family practitioners, district hospital physicians and nurses concluded that it is rare for women to come for the screening voluntarily. Mostly, they visit after they started to notice some symptoms and signs.

Women who are seeking OBGY care are increasingly from the younger generation and the following factors relate with it: teenage abortion, having multiple sexual partners, incomplete treatment for pre-cancer conditions and incomplete and poor quality of treatment of gynecological diseases.

*Case14*
- I have been working as a wound care nurse and I have noticed that recently even young girls are affected with CC. Five years ago most of patients were over 35 years’ old women. Now most patients are only at their early 30s and even in their 20s. In seldom cases they were teenage girls. Due to a poor control of abortion pre marital abortion has increased and there is no advice before and after abortion provided.

Women from urban areas usually come alone for their first screenings. Because of cancer suspicion women from countryside come to the third referral hospitals with family members or relatives who also assist them to navigate around the city. In certain cases if women have pelvic inflammatory disease or are infected with sexually transmitted disease they come alone in order to keep this health condition private. Nevertheless, women who are diagnosed with cancer require mental support; therefore, they tend to visit with their husbands and family members regardless whether they are from the countryside or city. Approximately, 60-70 percent of total women visit with somebody and 30-40 percent of them visit alone.

3.3.2 Results on specific questions for key informants who perform the CC screening

Key informants usually start their sessions with questions about their patient’s health related complaints. After the initial step they explain the test process. Most of the patients understand it without further explanations. Sometimes for elderly citizens and for women from countryside there is a need to explain several times.

Case15
In general when women come for the screening they have some kind of fear. For example: when we perform colposcopy exam they look very nervous and scared. Therefore, physicians and nurses explain in detail what they are going to do and it is important for us to make them understand that biopsy is not painful at all.

The majority of women do not have precise information about the CC screening process. Only a small percentage of women have heard by radio or seen on TV when specialists talk in health education series about CC.

Case16
The general population lacks knowledge about CC. There is no specific research that has been conducted; therefore there is no concrete number and statistics. Lots of women acquire false information through their friend’s knowledge about CC. Primary health care services should have information boards that provide detailed information about CC, its clinical signs and symptoms and CC screening.
If the first referral hospitals can distribute these information and provide detailed recommendations patients will have a more clear understanding on what awaits them at the third referral hospital. In addition, it would significantly reduce the burden from the third referral hospitals.

3.3.3 Procedures in the CC screening process

Most women who come for the CC screening have fear and they are anxious; therefore, it is essential to explain the situation in a detailed and honest way. Sometimes because of the workload physicians are very capricious and unkind. Health care providers answered that if patient have fear physicians and nurses should be kind and comfort them, if patient is shy health care providers should make them confident and if the patient is arrogant it is still necessary to explain the real situation.

Physicians and other health care providers at the third referral hospitals explain the final screening results to patients. They tend to explain the result differently based on their personality. First the health care providers inform about the results to the patient and then they would explain to family members and relatives if they see it is necessary. Women respond to the bad result as scared, anxious and sometimes they even cry.

Case 17

Physician’s duty is to explain patient’s situation and the problem in detail and in honest way. Women do not know what is cervix and vagina. So, we explain very detailed and tell them exactly where the cancer is located and what kind of treatment we can offer them. After the explanation particular patient feels better and gets confidence for further treatment.

Family group practitioners and district hospital physicians refer patients to the next referral hospitals for further diagnostic tests. Once the diagnosis is confirmed at the referral hospital the patient will be admitted to this particular hospital. After the patient is discharged from the NCC they are on district hospital’s oncologist follow up with scheduled visits.

The NCC’s physicians examine patient’s clinical signs and symptoms and send tissue for biopsy. Some additional tests might be ordered to confirm the final diagnosis. Once the diagnosis is confirmed the physician gives the recommendation on the kind of needed treatment. Subsequently, they decide where the patient should go, either in-patient or out-patient department. Treatment options are chemo-therapy, radiation and surgical treatment.
For the second screening visits women are well prepared and they have a better understanding than in their previous visit. Therefore, health care providers give very general information about the CC and focus on detailed information about the treatment.

**Case18**

*Explaining diagnosis in a right way is crucial. Depending on their understanding especially misunderstanding, women refuse to have treatments. Therefore, we have to be tactful about our explanations on CC treatment.*

There are no set rules and regulations on interviewing the incoming patients about their reasons for taking the CC screening; therefore, physicians never ask the reasons for coming to screening.

**Case19**

*There is no rule that requires determining the screening reasons why women come for the screening. Legally it is not required, so we cannot force people to come for screening. Generally, most women undergo screening because someone close to them was affected by the disease or when women become pregnant they go to hospital. Sometimes women go to hospital to get information on how to prevent unwanted pregnancy. Otherwise, women tend not to come to hospitals voluntarily or for preventive measures. Women come after they have some information or if they have some symptoms.*

### 3.3.4 Information seeking behavior at the site of screening services

In the waiting room for CC screening there are no posters or booklets about CC available but in general there is some information about cancer and women tend to read it while they are waiting for their appointment.

**Case20**

*There is no information materials provided in the waiting rooms. There is no designated dressing room; therefore, patients change their clothes in a bathroom door area. People always criticize about this condition. Forget about information exposure hospitals cannot even provide dressing rooms and women who come for the screening go from corridor to corridor.*

According to the NCC physicians and other health care providers most women who came for the screening never ask how they perform the screening and about screening process. But women who are referred to district hospitals ask the physicians and health care providers about screening procedures.
Case21
Very few women ask questions. Especially women from the countryside are generally shy and they never ask questions unless we talk. They tend to ask about their current conditions and future treatments. Maybe most women leave it to their doctors and they just do not ask questions although they had so many questions to ask.

Case22
Nobody asks about how I will examine her; therefore, when a patient comes in, we generally instruct them step by step. After that we start our exam. We never explain how we perform colposcopy. Some patients did not even notice when we take tissue for biopsy.

Women’s support group such as relatives and husbands also mentioned that there are no information materials about CC and CC screening in the waiting rooms. Thus women exchange information about their illnesses during their short stay in the waiting rooms.

3.3.5 Perceptions of key informants on knowledge and HSB of women

Women have no knowledge on what causes CC. But because of their fear of probable cancer they seek health care when they have the following signs and symptoms: pain during sexual intercourse, long lasting menstrual period, menstrual cycle change, heavy discharge, bleeding and lower abdominal or pelvic pain. A fairly large number of women admitted visiting monks for treatment.

Treating cancer at home is dangerous and women may use different kind of alternative medical methods which may create various complications. Therefore physicians are strongly against home treatment and self treatment.

Since initial symptoms are similar to gynecological problems women always seek care from the private and government hospital’s gynecologists. From there, they visit to their district hospitals and the NCC. In most cases women prefer to go to the NCC directly.

Case23
...Due to long lines and slow service most women prefer private clinics.
After noticing very obvious signs and symptoms like bleeding, heavy discharge and pain most women seek care and visit hospitals for CC screening. Some organizations organize annual health check-ups.

Physicians and other health care providers concluded that the following reasons would postpone women’s health screening: busy lifestyle, poor self care, lack of knowledge and information about CC screening, do not have any obvious complaining, uninsured and lack of financial capacity etc.

Most women know that CC early screening would provide an opportunity to treat and to prevent from complications; thus they believe CC is treatable.

In recent years, women have better understanding about CC early diagnosing benefits; therefore, they tend to visit to hospitals for voluntary screening. In addition, they want to have a biopsy if possible.

Women would like to know the result immediately after screening. First, women discuss treatment options and healing process with the physicians and nurses then they share the news with their husbands and their relatives.

During the screening some women do not know where exactly the CC is located due to the lack of knowledge about CC cancer. Therefore, they have no concept from where the sample for biopsy is taken. Additionally, there is some evidence that they have the misconception that alternative medicine or hypnosis can treat their cancer.

Women receive information about CC screening from health care organizations, non-governmental organizations, mass media and internet. Also they get information about CC treatment from their physicians and fellow women who are going through similar treatment.

3.3.6 Key informant's recommendations on increasing demand for screening

Key informants believe that if hospitals can provide a convenient individual exam room and the time for the single patient is sufficient screening services can improve. On the other hand, if health care providers are kind and exam costs reasonable then women can recommend the particular hospital to others.

In order to improve CC screening and information about CC:
• To organize CC screening at the first referral level hospitals and to send written invitations
• To train the first referral hospital physicians and nurses to provide necessary information.
• To do health education sessions in cooperation with district administration
• To educate and to advertise via mass media
• To add classes about cancer screening or cancer in the high school program
• To improve health education among the general population
• To improve the technology and to upgrade laboratory capacity
• To establish a mandatory screening system for new employees.

The following trainings should be provided for health care providers who work at the cancer center:

• Health care provider’s attitudes and ethics
• Counseling skills
• Stress management methods
• Cancer diagnostic methods
• Cancer prevention methods.

Women should acquire information about CC screening through physicians, other health care providers, health care service volunteers, and district and sub district governors, social workers and through non-governmental organizations.

Biopsy should be accessible at all referral level hospitals particularly country physicians and nurses should be able to perform biopsy. In order to do a biopsy they need to have an advanced training on performing biopsy. Key respondents also concluded that better encouragement and confidentiality, convenient environment, good ethic and constant training and advertisement could increase the number of women who want to undergo the screening.

Case24
Hospitals should have a better appointment system to avoid long lines. Hospitals should provide a possibility to screen 7 days of week and when physicians and nurses work during the weekend they need to have extra days off based on how many weekends they worked.
Key respondents developed the following recommendations for the first referral hospital’s physicians and nurses:

- To organize CC screening and to encourage women to participate actively
- To educate women and to advertise CC prevention
- To refer patients to the next level referral hospitals if necessary.

Specialized hospital’s and screening hospital’s duty is to transmit information about CC treatment options.

It is required to develop CC treatment posters, leaflets and booklets and to provide all of these materials to all referral hospitals. Such information materials should be placed in the waiting rooms of all three referral hospitals, in waiting rooms of OBGY exam rooms, in physicians’ offices and in community places. Moreover, to create a CC screening calendar and to provide health education programs about CC screening at hospitals.

Information about CC screening and CC treatment should be provided for men as well. For example men should know about: CC causes, early screening advantages, to encourage wives to go for screening and to provide emotional support.

3.4 Results of interviews with men and husbands

In general, men lack knowledge about CC screening. They answered that health care organizations and specialized physicians should be responsible for women’s CC and they should work primarily for prevention. Very few of them told that women themselves should be aware and should take preventive measures.

Husbands of women who were affected by CC understood the situation and were very well informed about CC and its screening. In contrary, male participants whose wives were not affected by the disease had very little knowledge about CC. Most of people are likely to receive CC information from newspapers, journals, radio and TV. People who visited the cancer clinic got their information from their health care providers.

Many of them do not know what causes CC. Most men thought that abortion, women’s hygiene, sexually transmitted infectious diseases, having multiple sexual partner and constant chills were main reasons for CC.
For them the reason to be at the hospital was that their wives were complaining about pain, particularly pelvic pain, fever, heavy discharge and other gynecological inflammatory diseases. The men agree that it is important for women to visit hospitals with their husbands. Husbands should be a big support when women have health problems like CC. When women get sick they should share bad and good news with friends and family members.

*Case25*

...Of course when she is sick, I take care for her. Also show her mental support and allow her to share her problems with someone who can relate. I encourage her to go and see a doctor...

All male participants in the study answered that information about CC should be widely available. There is an enormous need to know about CC causes, CC signs and symptoms, its negative effects, CC diagnosis and treatment. They informed that newspapers, journals and mass media need to advertise commercials and health education series constantly. Also children should know about cancer and CC from their high school education program.

*Case26*

Men should know what CC is and CC screening. Proper knowledge is the key. Information about CC should be published in newspapers, journals, and broadcasted through radio and TV. People should know what causes this disease. Not only men, children should know about CC through their school educational programs. On TV during H1N1 epidemic they advertise about H1N1 infection so well. They should use similar approach with CC...

*Case27*

...I believe men should know about this subject. Because we both have to carry the burden and both of us are responsible for the disease....

### 3.5 Results of observation

There were 2 cabinets for cancer screening at the third referral hospital. In these two cabinets women were examined by gynecologist doctors and the environment was very clean.

In the waiting room there were only four chairs and it seemed insufficient. One cabinet had a designated dressing room but the other cabinet did not. The dressing room was located right next to the examination room; therefore, once they change their clothes they moved to the
examination room. For the other test room women needed to change their clothes in a restroom area.

In the waiting room women were sharing their stories about what brought them to this particular hospital, about their symptoms and what kind of treatment they have been getting, how many times they came, whether they will have surgery or not, after medical and surgical treatment whether there is positive result or not. Some women were not actively involved in such conversations. The most frequent questions were: Is the doctor examining in this room? Who is the last person in the line?

In a waiting room area of OBGY cabinet there were not any information desk, posters, and handbooks about CC screening or treatment. Therefore, there was no opportunity for the women to receive information about CC while they were waiting.

Patients were not invited to the room kindly instead women went inside themselves when the previous woman came out.

Physicians at gynecological clinics were overcrowded from 9 a.m. until 1 p.m. Depending on patient’s state, signs and symptoms physicians spent around 15-20 minutes per patient. Patients made an appointment at the reception area. Women entered the OBGY cabinet according to their numbers.

Depending on the physicians’ examination period per patient women had to wait for 30 minutes up to 1 hour outside of the physicians’ office. But after 2 p.m. due to fewer patients women were able to enter the examination room in much shorter time.

Physicians gave their patients specific instructions about the next follow up session and what kind of treatment will be conducted during the next session. If women were waiting for their test results, physicians were telling patients what time they should come back for the test results.

The OBGY examination room of the second referral hospitals was slightly unclean and the overall environment was not comfortable. There were three OBGY cabinets and outside of these cabinets there is a seating area which had an insufficient number of chairs.

There was not any specific waiting room for female patients; therefore, women were waiting in the seating area of the hall. Some young women who were visiting for the first time were accompanied by their husbands. There were no CC prevention and treatment posters on the walls of the hall and no handouts or leaflets were available. Women were often reading other posters that were hanging on the wall like how to prevent Influenza A, virus subtype H1N1 infection, when to seek care, what are life threatening signs and symptoms, when pregnant women should come for OBGY exam and follow up, how to prevent unwanted pregnancy, different pregnancy prevention methods and preventive methods for sexually transmitted infections.
Since hospitals have an appointment system at the reception area patients get doctor’s examination according to their appointment number and numerical order. If a patient does not have an appointment number the physicians will not examine her. It was noticed that the majority of patients at the second referral hospitals were pregnant women who are or were going to be on pregnancy follow up.

Pregnant women at the second referral hospitals were having discussions among each other about how many children they have, whether it is their first or second pregnancy, on what kind of things they have to be careful during their pregnancy, whether they want a boy or a girl, ultrasonography and other laboratory test results, what kind of treatment did they have after pregnancy and how to take care of infants. According to their conversations only a few of them came for pap-smears or treatment. The women who came for such treatments were not talking to each other. The average waiting time was 20-30 minutes per person. There were a special dressing room and restroom for all patients.

The first referral hospitals were clean and comfortable. There were a few chairs in a waiting room for patients. Older citizens, pregnant women and children with their parents were present in the waiting room. Women were having a conversation about their children, what signs and symptoms they have and what kind of treatments could be effective. Some pregnant women were talking about whether it is their first or second pregnancy and where and what kind of laboratory tests they need to give for follow up. Elderly were speaking about their high blood pressure and their need to have intravascular BP medicine or grandchildren’s cough etc.

Family group practices do not provide CC screening services. There were no OBGY beds at the observational site. There were posters on the wall about how to prevent Influenza A virus subtype H1N1 infection, when to seek care, what are life threatening signs and symptoms, when pregnant women should come for OBGY exam and follow up, how to prevent unwanted pregnancy, different pregnancy prevention methods, preventive methods from sexually transmitted diseases and general information about reproductive health in the general waiting hall. There were no posters, leaflets and handouts about BC and CC screening and BC and CC treatment.

Some women read different handouts and took some of those handouts with them when they were leaving.

Women were lined up for family practitioner’s examination and when the previous person came out from the examination room the next patient went inside. There is no real appointment system. The waiting time is approximately 15-20 minutes per person. The family group practitioners were giving instructions to pregnant women on when to come back for a follow up. There was no special dressing room and the restrooms were public restrooms.
4. SUMMARY OF CONCLUSIONS

The following paragraphs summarize the main findings of the study:

- Study participants such as women, men, physicians and other health care providers believe that the CC morbidity has been increasing among women and that even the young generation is being increasingly affected by it. One of the primary reason for the significant increase in the number of women who seek diagnostic and treatment care in the OBGY hospitals is the improvement in women’s health education due to physicians and health care provider’s cancer recommendations in various publications and by mass media. Another reason is the increase of the cancer rate among the general population.

- The CC screened group and non-screened group of women that participated in the study have inadequate information and knowledge about CC, its screening, screening exam details, advantages of the screening, CC causes, signs and symptoms and its prevention. It is also recognized that there is no information available on CC as well as there was no knowledge on potential information sources in the case that the information is needed. After the screening women have better understanding and knowledge about CC. Men also have a lack of information about CC screening and CC information sources.

- Information materials as booklets, leaflets or posters for patients were not present at all referral level hospitals and other health care organizations.

- Mental and moral support is an important factor in women’s health seeking behavior. Physicians and other health care providers, family members and friends need to be encouraged for supporting women in their health behavior. It was stated that certain physicians’ are unkind and presented an unfriendly attitude which affects women’s health seeking behavior in terms of CC screening, prevention and treatment.

- The major reasons for women not taking advantage of CC screenings are the following: lack of knowledge about health screening, poor health preventive attitude and in particular seeking health care services after explicit signs and symptoms, financial constraints. Some women mentioned that they expect or wait for a special health screenings to be organized for them. Furthermore, women who live in the countryside are often isolated and their local hospitals lack CC screening capacity.

- The first and the second referral hospitals are not providing CC screenings. The main reason for that is the lack of special skills of the health providers at the first and the
second referral hospitals, inadequate diagnostic and treatment equipments and tools and the lack of related regulations.

- During the diagnostic process at the hospitals women always face the lack of information about cancer, where to go for the screening and how often they should visit doctors for preventive and follow up exams. It is essential to explain the importance and procedures of diagnostic tests and to educate patients on the causes of cancer and treatment process.
5. RECOMMENDATIONS

In this chapter a summary of recommendations on activities is provided. The recommendations focus on suggested activities for the improvement of CC prevention and screening in Mongolia based on the findings from the presented study. The following sections refer to recommended activities on the different levels, ranging from the structural preconditions, to the capacity building on the level of health care providers and the distribution of information for behavior change communication on the population level, under consideration of the roles of schools, workplaces and communities.

**Structural Preconditions:**

- To create regulations and a legal environment that allows health professionals to perform CC screening at the first and the second referral hospitals.

- To train the first and the second referral hospital’s physicians and other health care providers for CC screening methods and to provide them with necessary screening equipments and tools.

- To reduce the current overburden at the third referral hospitals, there is a need to increase CC screening accessibility and availability at the PHC units and at the same time increase the number of doctors at the third referral hospitals. This should be supported by the creation of a friendly and comfortable environment both for health professionals and patients.

- To initiate and implement a regular screening schedule e.g. annually to encourage women to go for CC early prevention screening.

- To equip all level hospitals with CC related awareness raising materials such as posters, leaflets and handouts.

**Capacity building by trainings of Health Care Providers:**

- To build capacity by trainings that will enable the basic diagnostic work up at PHC providers facilities such as bagh (smallest unit of the administration), soum (town) primary health care units, the family group units, district and province hospitals.

- To improve physicians and health care provider’s knowledge and skills on CC and its screening and related tasks by provision of trainings on these issues including vaccination, cancer causes, signs and symptoms, CC diagnosis and treatment.
To improve physicians, nurses and other health care providers’ attitudes and ethics by the organization of trainings on counseling skills, patient centered communication and ethics.

**Distribution of information for Behavior Change Communication:**

- To provide information about CC preventive screening by IEC materials and distribution to the population by the application of various communication strategies. This includes the improvement of the accessibility and availability of IEC materials at the PHC units on CC, CC prevention, CC screening, the explanation of procedures and treatment through the health care providers.

- To provide education for the general population about benefits of early CC screening and prevention as preventive measures and vaccination. This might be done by the following activities:
  - To conduct an awareness campaign to increase the knowledge of the general public on CC, screening and advantages of early screening and diagnosis in a constant and effective way.
  - To promote vaccination by the conduction of vaccination campaigns.
  - To maintain and strengthen the supportive attitudes of men towards screening and prevention activities and promote via them early preventive CC screenings for their female relatives.

**Schools:**

- To implement CC prevention and screening topics in reproductive health related school health education.

- To introduce CC, CC screening, CC treatment through parents and teachers at an adolescent age regardless of gender following a healthy schools setting approach.

**Workplaces:**

- To promote the prevention and screening by preventive and screening activities in or together with workplaces and companies.
Communities

- To promote CC screenings and support active screening participation by concerted prevention activities on the community level with involvement of volunteers and NGOs.

- To encourage CC prevention and CC screening seeking behavior by the coordination of CC related screening and prevention activities with other reproductive health activities on the community level.
REFERENCES

10. Grindl Dockery &Sally Theobold, Beyond Deductive Reasoning to greater Meaning: The Challenge in Public health for meaningful research & inclusive practices


24. CC diagnosis and treatment MNS 5855-2:2008


ANNEXES

INFORMED CONSENT FORM

Title of the study: Health Seeking Behavior Study of CC screening in Ulaanbaatar

Funding resource: Millennium Challenge Account Mongolia

Length of Interview participation: 30 minutes to 1 hour interview

Target Number of Subjects in the Study: 6 -12 women or physicians in the one FGD

Introduction

This study will provide important information on knowledge, attitude, and practice about cervical and breast cancer in general population and develop strategies to reduce and mitigate negative behavior and promote positive behavior. You are invited to participate for the study as a volunteer participant and all information are confidential.

Purpose

The main objective of this study is to determine women’s knowledge, attitude and practice when they have signs and symptoms related with CC and where to go for health care services. On the other hand, to find out health care providers hypothesis why women do not use CC screening, and know about causes and risk factors.

Advantages of study participation

The results of this study may help us to identify knowledge, attitude and practice to get health care and preventive services, and it may help us create helpful methods for promoting health of the people.

Risks of the study
There will be no health and career risk to you associated with participating in the FGD and key informative interview.

Confidentiality

Your privacy is important to us. When we record your answers to our questions in the survey, we will not put your name on that notebook. Instead, we will use an identification number so that someone who looks at the information does not know that it is you. All researchers who will have access to information about you will sign a document promising that they will not reveal this information or mention your name or indicate in any way that you are a participant in this study when they talk to others (see the list below of people who may have access to your information). Your personal information will be kept confidential and stored in a locked room.

After you signed on consent form you may want to refuse. If so please call the research team.

Costs of the study participation

Participation in this study is free. If you have to travel for any activity related to this research, we will pay for those costs.

Our contacts

If you have any questions or concerns about your rights as a participant in this research study, you may want to contact with the following people: Dr. Chimedsuren Ph.D, Associate professor. Director of SPH at HSUM and Dr.Erdenechimeg, Ph.D , professor of IPH at MHSU. They will answer all of your interested questions. Our address as follows:

Institute of Public Health
Zorig street –3, Sukhbaatar district
Ulaanbaatar, Mongolia
Phone: 976-11-329126; e-mail: e_chimgee71@yahoo.com

Voluntary participation/ withdrawal:

Your participation is completely voluntary and you have the right to refuse to be in this study. You can stop anytime after giving your consent. There are no harmful consequences if you decide to stop participating in the study. A researcher may stop taking interview you or drop you
from the study if they learn that you are not eligible to participate. There are no harmful consequences for you if the researcher decides to do this.

Your signature below indicates that you consent to volunteer for this study. Please notice that there are two boxes with instructions inside.

If you want to volunteer for this research, please sign below

____________________________________  ___________ __________
Subject’s Printed Name                            Date

____________________________________
Subject’s signature                            Date

IT IS INVALIDATED WITHOUT APPROPRIATE STAMP OF SPH.
Annex 2

Topics related to CC women aimed at key informants working at CC screening services

<table>
<thead>
<tr>
<th>General information and observations made by the key informants in C screening services</th>
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<tbody>
<tr>
<td>Average number of women on weekly basis for C screening</td>
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<tr>
<td>More women now that say two years ago</td>
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<tr>
<td>If the same, could you explain why that is?</td>
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<tr>
<td>If more, what could be the reasons behind this trend?</td>
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<tr>
<td>Indication of the age group of women</td>
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<tr>
<td>Compared with two years ago, has that changed? If so, could you explain why? If no change, explain why?</td>
</tr>
<tr>
<td>Are women usually coming alone or with someone?</td>
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<tr>
<td>If women are coming with someone, who would that normally be? (Relatives/ male/females)</td>
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<tr>
<td>Why would women prefer to come with someone else?</td>
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<tr>
<td>If women come alone, what could be the reasons?</td>
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<tr>
<td>The % of women who have been referred to and the % of women who come directly and spontaneously to the facility?</td>
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</tbody>
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<table>
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<tr>
<th>Specific questions for key informants actually applying the C screening</th>
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<tbody>
<tr>
<td>Can you tell us what exactly you are telling women before you apply the actual screening procedure?</td>
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<tr>
<td>Do women understand what you explain? If yes, how do you know? If not, why not and how do you react?</td>
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<tr>
<td>What is the most difficult part of the screening for the women under investigation?</td>
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<tr>
<td>Do you think women have been informed about screening procedures prior to the screening? If yes, by whom?</td>
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<tr>
<td>How would you describe the feelings/thoughts of women? Is this normal?</td>
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<table>
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<tr>
<th>Procedures in the C screening services</th>
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<tr>
<td>How is “bad” news (negative result of the screening) told to women?</td>
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<tr>
<td>Women’s reactions?</td>
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<tr>
<td>Is the news told to women alone or to the woman and a relative?</td>
</tr>
<tr>
<td>How is the follow-up organized? And what are your experiences with it?</td>
</tr>
</tbody>
</table>
In case women are there for the first screening, how do you welcome them and how and what do you explain to them?

Are there procedures to ask women why they decided to come for screening? (Referral, symptoms, told by others)

**Information seeking behavior in the screening service**

Is written information available in the waiting room?

If so, can you show it to us/take a copy

Do women read (watch) the information?

Prior to the actual screening, do women ask questions about the procedures?

If so what kind of questions do they ask and to whom?

Are other people (e.g. relatives of women/spouses) in the waiting room reading the breast cancer screening information available?

When women are waiting for C screening, do they talk to each other? About what do they talk?

**Perceptions of key informants on knowledge and HSB of women**

*Distinguish between: How do you think that women feel/know etc? And what do you think about this knowledge/feelings etc. The first one reveals as to whether key informants can identify themselves with the women and the latter explores key informants’ attitudes (e.g. expressions such as “stupid”, “women are not informed”, “it are only village women”)*

How do women explain their complaints related to their breasts?

Do women know the causes of C cancer? If yes, which ones?

Do women know the symptoms/signs of CC?

Are you aware of home remedies used to “cure” CC symptoms? To prevent?

Where do women prefer to go to when they discovered CC signs? Why?

What are the main reasons for women to resort to CC screening services?

Why do you think that women delay such screening? (reasons?)

Why do you think that women with complaints about their cervix never resort to screening?

Where do you think women can go to for other (non-screening) examination of their cervix?

Do you think that women belief in CC treatment?
In your opinion, do women understand why they are being screened?

Do women know about the advantages of early detection of CC?

After having been screened, do you think that women are eager to get the results immediately?

With whom do you think that women would share this information with?

What kind of misconceptions do exist among women on:

*C cancer screening
*C cancer
*C cancer treatment

Where do you think women get information on CC screening?

Where do you think women get information on CC treatment?

Key informant’s recommendations on improving demand for C screening

What would be your recommendations for improving the information on C cancer screening? How could you contribute to a better understanding among women of the need for C cancer screening?

Do screening services have a specific role to play in increasing the women’s demand for C cancer screening?

Which kind of organizations or what kind of experts should be assigned for informing women on the need for C screening?

What kind of role should PHC staff play?

Which kind of organizations or what kind of experts should be assigned for informing women on the need for C cancer treatment?

Should C screening education be developed for male population? What kind of messages would you suggest?

Should C cancer treatment information be developed for the male population? What kind of messages would you suggest?
Annex 3

In-depth interview women with CC

Perception/knowledge on C cancer

- Is C cancer a problem in UB? If yes, how do you know? If no, why not.
- Do you know someone who has (had) C cancer? If yes, is she a friend, relative, neighbor etc? Try to find out how that person discovered it, what she did, try to discover the chain of HSB actions.
- Is there a treatment for C cancer? Is it available in UB and where? Is it expensive?
- How is the treatment like? Do you know side-effect? Is C cancer treatment effective?
- Would you be afraid of C cancer treatment? Why yes? Why no?
- Do you understand women with C cancer who refuses treatment? If yes or no, clarify?
- Can you discuss C cancer easily with other women/with children?
- How do women get C cancer? (Family matter, sexual life, alcohol, other habit, being unfaithful etc)
- Can C cancer be prevented? How?
- Can C cancer happen to you? Yes/no and why?
- Are there women with specific characteristics who are likely to get C cancer? Please the characteristics etc age, education etc.
- Are people gossiping about women with C cancer?
- How are women with C cancer usually regarded/treated in your community (health care providers, families, friends, relatives, co-workers)? Are people friendly or try to avoid her? Is there support from whom?
- Do women with C cancer feel ashamed to talk about it with her husband, female relatives and friends?
- What is more difficult to discuss with others (men/children): B or C cancer and why?
- Do you think that children (specify age and sex) should be informed about C screening, C cancer and its treatment? If yes/by whom and if no, why not.

Perception, misconceptions and knowledge of symptoms

- Which were the signs that encouraged you to go to a health care provider? What was your reaction and what did you do immediately after the discovery?
- Before going to a health care provider with whom did you discuss the signs?
- What kind of information did you have on “abnormal signs” and from whom or where did you receive this information?
- Did you “treat” your cervix at home prior to going to health care provider? What did you do and who advised you to do so?
- Did you discuss/inform your husband? How did he react and what was his advice if any?
- What were your feelings while discussing these signs? (Details)
- Could you prevent the abnormal signs and How?
• Did you know where you could go to in case you feel “abnormal” signs in your cervix?
• Did you ever hear about C cancer screening services? If yes details (where, costs, what do they do, for what reasons and where did you get this information from?)
• Did you ever consult these services when you discovered abnormal C signs? Why not? Why yes? Alone or with whom?
• What kind of information on C cancer screening would you need and from whom/where would you like to receive this information from?
• Do men need such kind of information? If no, why not? If yes, why and what kind of information? If no, why not? If yes, why and how to manage it?
• Would there be any reasons for you not to go for C cancer screening?
• What kind of reasons would other women have who are not going to screening? Ask details?
• Do you think that children (and at what age girls and boys) should be informed about C cancer screening, about breast cancer and about C cancer treatment? If yes by whom? If no, why not?
• Would you go to CC screening even without having “abnormal signs”? 
• Did you know how they actually do the screening? Did you think it is painful? If yes explain?

Actions before screening and experiences with CC screening

Key Questions

• Could you recall the details on what happened between discovery of “abnormal signs” in your cervical and your entrance in this screening/treatment centre? (Ask all the details E.g.…… Went to general practitioner, received tablets ……… respondent went back … general practitioner referred to screening centre…… again delay due to …etc).
• If the respondent visited other health care providers prior to the screening, how would she describe the interaction with that provider? (Ask details on attitudes/referral/information provided by health care provider etc.)
• Before going to the C screening did you have information on screening centers and procedures? If yes, where did you get this information from? From whom?
• What did this information tell you?
• Is information on C cancer screening important for taking the decision to go for screening? Explain why? Suggest what kind of info would be help?

Screening services

• Where did you go for screening? Place you preferred to go to?
• Describe the waiting room etc. Was information available (posters pamphlets, video)?
• Where more women waiting for screening? Age group?
• Did you go with someone? With whom and why? Or why alone?
• Could you ask questions on screening procedures? To which person in the screening center?
• If yes, did you ask questions and which kind of? If no why not?
• Did you talk to other women? If so what did you discuss?
• Do other people in the walking room, read information on C screening?
• The health care provider who is doing the screening, did he/she talk to you? Did he/she explain what you had to do? Please, repeat? Did you understand his/her explanation? Do screening personnel welcome you properly?
• How did you feel while waiting for the screening?
• What is the advantage of breast cancer screening?
• Where did you eager to receive the results? If yes, why? If no, why not? With whom did you share these results? And their reaction?
• Can you imagine that other women are reluctant to go for screening? Give as much reasons as possible.
• Did you hesitate to go? Was there delay? Why?
• Did you receive information or follow-up screening? If yes, what kind of? Would you go for a second time? If no, please explain,
• Do you think that children (age, boys, and girls) should be informed about cancer screening, cancer and its treatment?
• Please give suggestions on how/why screening services could improve?
• Having gone through screening, what kind of information was lacking? Would you have needed before going?
Annex 4

FGDs aimed at women and key informants

1. What kind of reasons could hinder women to resort to services for CC screening? The interviewer could list all the possible reasons mentioned by the participants and ask the FGDs’ participants to put them in order of importance.

The interviewer could add a few reasons (economic, transport, availability and accessibility of services, public versus private services, lack of support from family members, lack of knowledge about advantages of screening, fear for screening and B cancer) and which of these reasons could be easily lifted and how?

2. How would the most ideal CC screening centre look like with respect to staff, welcome procedures, information sharing etc? In short, describe a centre where you would feel most comfortable and would recommend other women to go to.

3. How could staff of CC screening services deal with

* Fear,
* Uncertainty,
* Shame
* Ignorance
* Misunderstanding

4. What kind of suggestions do you have for training of staff employed in CC screening centers?

5. What kind of information on CC screening would you need and where should this be available?

6. With respect to “abnormal signs” what could be the reason for women to resort to:

- Pharmacists
- PHC units
- Private clinics
- Public hospital
- Gynecologist
- General practitioner
6. Use outstanding statements of either women or key informants as topic for the FGDs

7. For key informant only;

The frame of procedures in the centre can be used as a basis for discussing perceived fields that are in need for improvements. Let the group discuss how improvements could be achieved and what exactly would be needed?
Annex 5

Observation

An important source of qualitative data is direct, first hand observation. If feasible, observations could be made in waiting rooms of screening services. Observation needs careful preparation and the observer should be skilled in reporting the nature of events in an accurate and reliable manner. The observation should be focused and may increase the possibility of triangulation.

A guideline on what to observe is needed and could include:

- Describe the physical environment without an evaluative statement such as crowded.
- Is there any room for changing clothes?
- Is there any toilet for women?

- Do women in the waiting room talk to other women and on what kind of subjects?
- Are posters, pamphlets, booklets on cancer screening and treatment available in the waiting-room?
- Are pamphlets, booklets used by the women in the waiting room?
- How are women invited to the screening room?
- How long (how many minutes) one woman is waiting for screening?
- Do they take appointments with women?
Annex 6

Semi-structural interview for male participants

1. In your opinion, CC are how common and what do you think about epidemiology of those conditions? Where do you think you can find this information?

2. Tell me about how proper and well do screening held in Mongolia? Do you know about cancer screening? What organization and who should perform the screening?

3. What are causes of CC? How people affect by these conditions? Please list all possible causes.

4. What signs and symptoms does your wife have? Does she complain a lot and feel like you should support more?

5. What do you do when she is complaining with these signs? How do you support her? Whom do you share about the situation?

6. Do you think it is important to provide CC information for men? What kind of information would you like to know? Where the information should create?
Annex 7

Additional recommendations of FGD

- Recruit participants according to the recruitment strategy
- Set up recording equipment and the room where interview will take place (interview room will be prepared at the hospital or at the khoroo which is smallest units of the administrative units)
- Researcher (2 field staff work there: someone facilitates interview and another takes note) being prepared to answer any questions participants may have about the screening breast and cervical cancer
- Arrive on time, equipped with the recording equipment, notebooks, and interview guide.

Conducting the FGD and Interview

- Greet the participants in a friendly manner
- Brief describe the steps of the interview process (informed consent, questions and answers, their questions and reimbursement)
- Obtain informed consent from each participant before starting interview
- Turn on the tape recorder and verify that is working
- Conduct the interview according to the interview guide
- Ask follow-up questions and end the question-asking phase of the interview
- Give the participant the opportunity to ask questions
- Reconfirm the participant’s consent while the tape is still on
- Clarify any factual errors expressed by participants during interview
- Reimburse or give financial compensation for the participation (Note: if not give reimbursement they do not come to the FGD and interview, if questionnaire survey that is no problem) (not cash, it may present/gift)

After FGD and interview

- Check the tape and notes were recorded well, if it is not well expand it
- Make sure all materials labeled
- Debrief with other field staff
- Assemble all materials into one envelop. Double check that you have completed all forms and materials
- Note and expand any missing materials
- Expand your notes after each interview (within 24 hours)
NOTE TAKER FORM FOR FGD

Date: 
Moderator:  
Note-taker:  

<table>
<thead>
<tr>
<th>Question or number of question</th>
<th>Responses</th>
<th>Observations</th>
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CHECKLISTS

Mark arrangement

- Room setting for FGD and interview
- Transportation of field staff to FGD and key informant interview
- Transportation of participants to FGD and key informant interview
- Refreshment for participants

What to take to the FGD and key informant interview

Equipment

- 1 tape recorder
- 2 bank 90 minute cassette tapes per interview
- Spare batteries
- Notebook and ball pens

FGD and key informant interview packet

- 1 large envelop
- 1 copy of interview or focus group guides
- Informed consent forms (For key informative interview it will be signed by interviewee and for FGD it will be signed by moderator)
- Participant’s reimbursement receipt

What to place in the envelope after FGD and key informant interview

- Signed informed consent form or oral consent will be recorded on the tape
- Labeled interview or focus group guide with notes
- Field notes
- Labeled cassette tapes, re-record tabs punched out
- Signed reimbursement form