

THE CLASS OF 1964 POLICY RESEARCH SHOP

# BREAST CANCER PREVENTION IN KOSOVO: UNDERSTANDING CAPACITY CONSTRAINTS AND IDENTIFYING POLICY OPTIONS FOR PREVENTION

PREPARED FOR THE MINISTRY OF HEALTH, REPUBLIC OF KOSOVO



*This report was written by undergraduate students at Dartmouth College under the direction of professors in the Nelson A. Rockefeller Center and the Dickey Center for International Understanding through the Global Health Policy Lab. For the past six years the Global Health Policy Lab, an extension of the Class of 1964 Policy Research Shop, has addressed health policy issues for the governments of Greenland, Kosovo, Nepal, and Peru. The PRS is fully endowed by the Dartmouth Class of 1964 through a class gift given to the Rockefeller Center in celebration of its 50th Anniversary. The PRS was previously funded by major grants from the U.S. Department of Education, Fund for the Improvement of Post-Secondary Education (FIPSE) and from the Ford Foundation and by initial seed grants from the Surdna Foundation, the Lintilhac Foundation, and the Ford Motor Company Fund. Since its inception in 2005, PRS students have invested more than 70,000 hours to produce more than 200 policy briefs for policymakers.*

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# GLOSSARY OF TERMS

**AMC** – Action for Mothers and Children

**BC** – Breast Cancer

**CBE** – Clinical Breast Exam

**ECIBC** – European Commission Initiative on Breast Cancer’s

**FMC** – Family Medicine Center

**GDG** – Guideline’s Development Group

**HCP** – Health Care Provider

**LIC** – Low-income country

**LMIC** – Lower-middle-income country

**MFMC** – Main Family Medicine Center

**MMG** – Mammogram

**MOH** – Ministry of Health

**NGO** – Nonprofit Organization

**UCCK** – University Clinical Center of Kosovo

**UIC** – Upper-income country

**UMIC** – Upper-middle-income country

**US** – Ultrasound

# EXECUTIVE SUMMARY

The National Institute of Public Health of Kosovo reported 4,409 incident cases of cancer in 2018, up from 2,308 in 2012.<sup>1</sup> Similarly, the Oncology Clinic of UCCK registered 1,483 cancer in 2018,<sup>2</sup> including 340 new cases of breast cancer, up from 1,237 cases two years prior to that. Forty-eight percent of these cases of cancer seen at UCCK are detected at Stage III or IV, resulting in poor treatment outcomes. It is also important to note that this incidence is high despite the particularly young population in Kosovo in comparison with other countries, with a median age of 29.6.<sup>3</sup> Therefore, because breast incidence increases with age, the burden of disease will only increase as the population ages and breast cancer will need to become a proactive focus of the health care budget.<sup>4</sup>

The Ministry of Health in Kosovo, in partnership with the National Board for Cancer Control, has invested in expanding clinical services to respond to its growing burden of cancer. However, they have identified prevention strategies as a gap in the current health policy domain. The main priority of the Minister is to identify key policy interventions that the MOH and the Government of Kosovo might undertake to improve the earlier detection of common cancers, specifically breast cancer. In partnership with Action for Mothers and Children (AMC), the Dartmouth Global Health Policy Lab team conducted a mixed-methods study to support the development of policy options for the earlier detection of breast cancer, specific to the Kosovo context.

## CURRENT CONDITIONS

The team researched the current conditions of breast cancer detection in Kosovo at each level of the healthcare system. The team identified *barriers* (what hinders the introduction of a screening program) and *opportunities* (points of intervention where Kosovo can take steps toward introducing and standardizing screening) that exist within the current healthcare system.

Barriers that limit breast cancer control include:

- Lack of awareness
- Stigma
- Lack of uniform infrastructure
- Limited human resources
- Lack of patient organization
- Communication between levels of care
- No national breast cancer prevention plan

Opportunities that decision makers can build upon include:

- Expand existing awareness efforts
- Leverage use of mobile mammography unit
- Train nurses to conduct CBE
- Expand use of risk questionnaire

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## POLICY OPTIONS

The team has designed policy options with the long-term goal of a national cancer policy to include screening. The goal at the primary level is to develop capacity so that they can provide mammograms on-site if resources are available, or refer patients to their district's regional hospital. Until then, it is important to improve early detection through CBEs. Primary-level physicians, who have a greater sense of their patient constituencies, may be best suited for raising awareness and sending invitations, for invitation-based screening. Options to facilitate this transition include:

- Awareness and education
- Increase CBE frequency at primary-level
- SMS texts to increase patient participation and retention
- Risk questionnaire

The goal at the secondary level is to provide mammograms on-site for patients referred from FMCs. Regional hospitals at the secondary level of the health system will need to confirm diagnoses of breast cancer through mammograms, on the referral of FMC doctors as well. Options to facilitate this process include:

- Mobile mammogram unit

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## CONSIDERATIONS

The policy options above were designed to bring Kosovo closer to the end goal of a national screening program, in which women ages 50 to 69 would receive a biennial mammogram, in accordance with various cancer policies in EU countries. However, as Kosovo builds capacity towards reaching this goal, Kosovo's Breast Cancer Prevention Plan should define its own end goal to ensure that this screening program is most effective for its population. To design a program to be tailored to Kosovo's own needs and resources, decision makers will need to consider:

- Delivery of screening services
- Target population
- Recruitment of women

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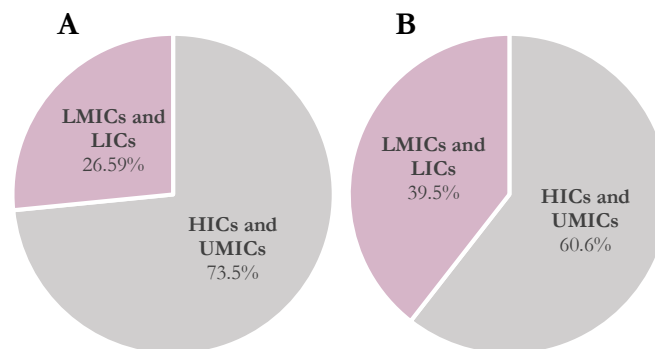
## CONCLUSION

As the burden of late-stage breast cancer continues to rise in Kosovo, a national screening program becomes increasingly important to respond to women's healthcare needs. This study aims to understand the current capacity constraints to earlier breast cancer detection and screening, and to identify key policy options for building the capacity to introduce to a national organized screening program.

# INTRODUCTION

## CONTEXT OF BREAST CANCER

The global burden of breast cancer is an increasing problem worldwide, and specifically impactful in low- and middle-income countries (LMICs). As the most common cancer among women globally, breast cancer represents about 25 percent of all cancer cases in women and is the fifth most common cause of death from cancer in women.”<sup>5</sup> Although the scientific knowledge regarding breast cancer and breast cancer treatment has lowered death rates in high-income countries (HICs),<sup>6</sup> breast cancer rates in low- and middle- income countries have yet to follow suit. Instead, the rate of breast cancer incidence in LMICs has been rising by up to five percent per year,<sup>7</sup> and more than half of the 425,000 worldwide deaths from breast cancer in 2010 were in LMICs rather than HICs.<sup>8</sup> This disproportion of higher incidence in HICs and higher mortality in LMICs is especially visible in a 2012 comparison of breast cancer for 177 countries (see Figure 1). However, breast cancer is a disease that, if diagnosed early and treated with appropriate methods, should not be a source of high mortality in a country.



**Figure 1. Total breast cancer (A) incidence and (B) deaths for 177 countries.<sup>9</sup>** According to data from GLOBOCAN International Agency for Research on Cancer (2012) and World Development Indicator (2014, 2015). Figure adapted from Bellanger et al.

Like many middle-income countries, Kosovo has seen growing rates of cancer and other non-communicable diseases. The National Institute of Public Health of Kosovo reported 4,409 incident cases of cancer in 2018, up from 2,308 in 2012.<sup>10</sup> Similarly, the Oncology Clinic of UCCK registered 1,483 cancer in 2018,<sup>11</sup> including 340 new cases of breast cancer, up from 1,237 cases two years prior to that. Forty-eight percent of these cases of cancer seen at UCCK are detected at Stage III or IV, resulting in poor treatment outcomes. It is also important to note that this incidence is high while the population in Kosovo is particularly young in comparison with other countries, with a median age of 29.6.<sup>12</sup> Therefore, because breast cancer incidence increases with age, the burden of disease will only increase as the population ages and cancer will need to become a proactive focus of the health care budget.<sup>13</sup>

Progress in cancer control in LMICs is limited by a variety of factors, including “poor healthcare infrastructure, competing health priorities, lack of cancer awareness, unabated exposure to carcinogens, inadequate funding, and human resource limitations in healthcare delivery.”<sup>14</sup> Due to this lack of cancer awareness and screening accessibility, cancer cases detected at late stages lead to increasing mortality rates. Women in LMICs face “various barriers to breast cancer care, from accessing early detection programmes to receiving timely diagnosis and appropriate treatment.”<sup>15</sup> As a result, the five-year breast cancer survival outcomes among women in LMICs are 40-60 percent as opposed to 84 percent in North America.<sup>16</sup> Therefore, it is imperative that countries like Kosovo focus on preventative and screening strategies in order to reduce risk factor-exacerbating behaviors and increase early stage detection in their populations.

According to Anderson, et. al, the low breast cancer survival rates in LMICs are “largely attributable to late-stage presentation and limited diagnostic and treatment capacity,” and “early detection and effective treatment are interrelated, synergistic, and mutually dependent strategies for improving breast cancer outcomes.”<sup>17</sup> Therefore, increasing efficacious screening methods must be coupled with accurate diagnosis, referrals, follow-ups, and higher patient retention rates.

The Ministry of Health in Kosovo, in partnership with the National Board for Cancer Control has invested in expanding clinical services to respond to Kosovo’s growing burden of cancer. However, they have identified prevention strategies as a gap in its current health policy service delivery system. The main priority of the Minister is to identify key policy interventions that the MOH and the Government of Kosovo might undertake to improve the earlier detection of common cancers, specifically breast cancer. The Global Health Policy Lab team conducted mixed-methods research to support the development of policy options for the earlier detection of breast cancer, specific to the Kosovo context.

## **PURPOSE OF BREAST CANCER SCREENING**

Cancer screening has a clear purpose: “to detect either precancerous lesions or preclinical cancer at a stage when therapeutic interventions are associated with better disease outcomes, such as prevention and reduced cancer-related mortality, respectively.”<sup>18</sup> However, in LMICs, where resources are often limited, breast cancer control efforts are complicated by the general lack of cancer awareness and/or active screening programs, limited data-collection methods, and resource constraints on treatments post-diagnosis. Therefore, it becomes important to consider the current conditions of Kosovo’s healthcare system to understand how to introduce most effectively a screening program into the system given the existing resources, and how to avoid introducing a program prematurely.

Over the course of policy development, it is important to keep the end goal in mind. As Shah et al. argue, screening programs must be equitable and economically efficient, and that “the health care infrastructure must be equipped to manage the increased case finding with respect to treatment, support, and follow-up.”<sup>19</sup> Specifically, they outline ten criteria to introducing a screening program as proposed by the WHO (see Table 1).



**Table 1. Criteria for introducing a screening program from the WHO.** Table adapted from Shah et al.<sup>20</sup>

<b>1</b>	The screening program should respond to a recognized need.
<b>2</b>	The objectives of the screening should be defined at the outset.
<b>3</b>	There should be a defined target population.
<b>4</b>	There should be scientific evidence of screening program effectiveness.
<b>5</b>	The program should integrate education, testing, clinical services, and program management.
<b>6</b>	There should be quality assurance, with mechanisms to minimize potential risks of screening.
<b>7</b>	The program should ensure informed choice, confidentiality, and respect for autonomy.
<b>8</b>	The program should promote equity and access to screening for the entire target population.
<b>9</b>	Program evaluations should be planned from the outset.
<b>10</b>	The overall benefits of screening should outweigh the harm.

Without these conditions, Shah et al. argue that screening programs may be a premature means to cancer prevention due to incurring extra costs, physiological effects, and more, which, in a LMIC may burden the healthcare system further.<sup>21</sup> As a LMIC, Kosovo may need to build capacity to meet the aforementioned criteria well, as a way to persuade women and providers of the efficacy of an organized screening. Kosovo meets some of the delineated criteria and not others.

# METHODS

The Dartmouth Global Health Policy Lab team, in partnership with Action for Mothers and Children, conducted a mixed-methods study to generate evidence to guide a national strategy for integrating breast cancer screening into Kosovo’s existing health care system. From January 4 to March 14, 2020, the team conducted more than 16 interviews with healthcare providers, public health officials, and administrators and conducted surveys focusing on resource capacity, administered to providers, and surveys about risk factor awareness, administered to women. The team organized site-visits to the following regions: Prishtina, Prizren, Ferizaj, and Gjilan. Specifically, the team sought to:

## **IDENTIFY THE AWARENESS OF BREAST CANCER RISK FACTORS**

The team surveyed 16 women in Prishtina to gauge Kosovar women’s awareness of breast cancer risk factors. This Risk Awareness Survey included questions about risk factor awareness more generally, as well as questions from the GAIL-Model, a breast cancer risk stratification tool, to better understand if such tools can be used in Kosovo (see Appendix A). Through these surveys, the team learned about women’s awareness of breast cancer risk factors which were used to further contextualize provider perceptions.



## **IDENTIFY RESOURCE CONSTRAINTS**

The team interviewed stakeholders, including hospital directors, physicians, and public health officials in Prishtina, Prizren, Ferizaj, and Gjilan to understand the resource capacities at various facilities. Specifically, the team developed a Resource Capacity Survey and administered it at each facility to compare human resources, provider training, and infrastructure (see Appendix B).

In order to understand the current level of prevention care taking place, the team assessed the current infrastructure and resources available by assessing what early detection methods are available (including mammograms, ultrasounds and CBEs), which health care professionals are trained to perform them, and which health care professionals most commonly perform them. The team also sought to understand if the GAIL-model or other risk stratification tools are used.



## IDENTIFY BARRIERS TO ACCESS AND OPPORTUNITIES FOR INTEGRATION

The team took a health-systems approach to look specifically at the feasibility of integrating breast cancer screening within the existing health system in Kosovo. Provider interviews took place with key stakeholders at each level of the health system, including Main Family Medical Centers and regional hospitals in Prishtina, Prizren, Ferizaj, and Gjilan.



These interviews were used to understand existing pathways to care and current screening and referral practices, as well as the opportunities and barriers to integrating breast cancer screening into existing activities and delivery systems. Specifically, these interviews focused on: pathways to care, health-seeking behavior, incentives to early detection, resource constraints, opportunities and barriers to integrate screening, and the feasibility and impact of various screening options. Listed below are the interview sites and stakeholders (see Table 2).

**Table 2. Interview sites and stakeholders.**

Region	Facility	Stakeholder
Prishtina	UCCK	- Director of Oncology - Breast Cancer Oncologists - Director of Radiology - Breast Cancer Radiologist
	Prishtina MFMC	- Director of MFMC
	Lipjan MFMC	- Director of MFMC
Prizren	Regional Hospital	- Executive Director of Regional Hospital - Administrative Director of Regional Hospital - Medical Director of Regional Hospital
	Prizren MFMC	- Executive Director of MFMC - Administrative Director of MFMC - Director of Prizren Municipality Health - Director of Radiology
Ferizaj	Regional Hospital	- Director of Regional Hospital
Gjilan	Regional Hospital	- Director of Regional Hospital

## PRESENT POLICY OPTIONS

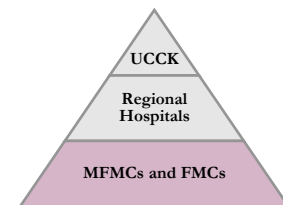
Using a health-systems approach, the team developed and presented policy options for integrating early detection of breast cancer into the current healthcare system. These options are organized to be sustainable dependent on the different levels of resources that may be allocated towards a breast cancer prevention program and provides an opportunity to build capacity gradually towards the end goal: a robust national screening program.

# CURRENT CONDITIONS

Although there is currently no screening program in place in Kosovo, various healthcare facilities have taken initiative to detect breast cancer earlier. Here, the team discusses the current conditions of breast cancer detection in Kosovo, specifically at the primary and secondary levels of the healthcare system. This overview of detection is followed by a discussion of the *barriers* (what hinders the introduction of a screening program) and *opportunities* (points of intervention where Kosovo can take steps toward introducing and standardizing screening) that exist within the healthcare system. Because breast cancer detection and/or screening is not standardized, each facility varies in resources, infrastructure, and protocols for early detection, regardless of its level in the healthcare system. Therefore, although the barriers and opportunities that are discussed exist at each facility, they affect each to varying degrees.

## CURRENT ROLE IN DETECTION: PRIMARY LEVEL

Without a screening program in place, breast cancer detection at the primary level takes place either when (1) a provider determines a test necessary, or (2) a woman asks for a test herself. However, these tests (e.g. mammograms, ultrasounds/echoes, CBEs) vary at each primary-care facility because resources are not uniform across each MFMC and FMC. Facilities that are equipped with appropriate resources adapt to deliver what services they can with those resources (see Page 13); however, there is no robust data on screening utilization across primary-level facilities.



At different facilities, the diagnostic process varies depending on the available equipment, provider's discretion, and the patient. Because there is no explicit protocol in place, providers use the methods they deem best fit. For example, some facilities require a CBE, followed by an ultrasound/echo or mammogram, if necessary. The breast cancer detection method used may vary across facilities depending on a woman's age as well. For example, women under 40 only receive ultrasound at UCCK, unless otherwise deemed necessary by a provider, while women 40 years or older are given mammograms.

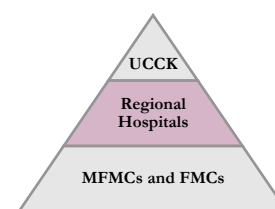
However, because MFMCs and FMCs are not usually equipped with mammography machinery, breast cancer detection commonly begins with ultrasound/echoes and CBEs. Ultrasound testing can occur independently or in conjunction with mammograms, and most commonly occurs for patients less than 40 years old. For CBEs, primary care doctors are trained to perform them, and occasionally nurses. Specifically, in Prishtina's MFMC, nurses are trained to conduct CBEs and commonly perform them; however, this is not the norm, as nurses at other facilities have not been reported to be trained to conduct CBEs.

In cases where providers are suspicious of malignancy after conducting examinations with the resources available to them, primary-level providers then refer their patients to either secondary- or tertiary-level care for further testing, such as a mammogram and/or biopsy, before a diagnosis is reached.

It is also the responsibility of MFMCs and FMCs to educate the patient population and spread awareness. The primary level is chiefly involved in the dissemination of information about breast cancer incidence, symptoms, and risk factors in their municipalities. For example, the MFMC in Prizren has a pamphlet to educate women on breast cancer risk factors, self-breast exams (SBEs) and routine mammography. Awareness efforts are strongest during Breast Cancer Awareness Month. For example, in the Lipjan municipality of Prishtina, the MFMC has collaborated with the local media to inform the public that screening is free in October.

## CURRENT ROLE IN DETECTION: SECONDARY LEVEL

Breast cancer detection at the secondary level takes place when (1) a provider deems a test necessary, (2) a provider at the primary level has referred a patient to receive testing at the secondary level, or (3) a woman asks for a test herself. Because primary-level facilities are not uniformly equipped with mammograms, providers often refer patients whom they suspect have breast cancer to their secondary-level regional hospital where resources are often more plentiful. Specifically, regional hospitals are equipped with more human resources (e.g., radiologists, thoracic surgeons) and machinery for breast cancer testing (e.g., mammograms, ultrasounds), as well as have other departments needed for diagnosis, such as pathology. However, without a protocol in place for breast care detection, pathways to diagnosis vary across the secondary-level system as well.



Similar to primary-level care, resources are not uniform. Specifically, while some regional hospitals have functional mammogram machines, thoracic surgeons and pathology departments, others are lacking. For example, in Gjilan, the regional hospital has an analog mammogram machine that is outdated and no longer in use as well as no thoracic surgeons—the specialists needed to conduct biopsies to diagnose breast cancer. In regions without functional mammogram machines, a mobile mammography unit has been used to supplement breast cancer detection and screening efforts, such as in Gjilan, where this mobile unit for one month during 2019.<sup>22</sup>

## CURRENT MAMMOGRAPHY MACHINERY

Using the Resource Capacity surveys at visited sites in conjunction with a report on the Mobile Mammography unit from 2015 (“Projeckti Ma-Mo 3”),<sup>23</sup> the team found that there are 12 static mammography machines and one digital mobile machine in Kosovo. Of the 12 static machines, three are digital and nine are analog; however, as of 2019, “there is no data available regarding their utilization rates, examination capacity, quality of imaging, or the degree of application of mammography standards.”<sup>24</sup>

Within the five-year time period between the “Projeckti Ma-Mo 3” report and this project, the team found that some resources are in different conditions than as stated in the 2015 report. Specifically, the team found that there is an additional machine in Lipjan MFMC and that the mammography machine in Gjilan is no longer functional.

As a result of these discrepancies, the team is unable to verify the functionality of machines in the following regions: Ferizaj, Gjacova, Mitrovicia, and Peja.

Table 3 and Figure 2 show existing mammography machines and if they are functional, based on provider interviews at regional hospitals and MFMCs; however, further research is needed to confirm these resources.

**Table 3. Mammography machines at each level of the healthcare system, by region.** \*Data taken from “Projeckti Ma-Mo 3” and has not been confirmed  
 \*\*Second mammography machine refers to mobile mammogram unit, currently stationed at UCCK.  
 \*\*\*Gjilan has an analog mammography machine; however, it is outdated and no longer in use.

Region	Level of Healthcare System	Number of Mammograms
Prishtina	Primary	4
	Tertiary	2**
Prizren	Primary	1
	Secondary	0
Ferizaj	Primary	1*
	Secondary	1
Gjilan	Primary	0
	Secondary	1***
Gjacova	Primary	0
	Secondary	1*
Mitrovica	Primary	1*
	Secondary	1*
Peja	Primary	0
	Secondary	1*



**Figure 2. Map of mammography machinery, by region.** \*Gjilan has an analog mammography machine; however, it is outdated and no longer in use.

The team identified seven system-level *barriers*, defined as components of the health system that hinder the introduction of a screening program. Because each facility varies in resources, infrastructure, and protocols for its response to breast cancer, the team finds that these barriers exist for the health-system as a whole, rather than at a specific level, and that they affect each facility to varying degrees. The team has organized these barriers as *patient-side*, obstacles that hinder a woman from electing to get a screening, and *provider-side*, obstacles that limit providers ability to offer a screening.

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### PATIENT-SIDE

#### LACK OF AWARENESS

Although providers perceive that breast cancer awareness is increasing among women in Kosovo, it is simultaneously seen as a barrier to introducing a screening program. Providers share that women often wait until breast cancer symptoms are severe or painful before choosing to see a physician. This delay in care-seeking behavior leads to many cases being diagnosed at stage III or IV, which is consistent with how 48 percent of breast cancer cases in Kosovo detected at late-stage nationwide.<sup>25</sup>

Without an existing screening program in Kosovo, earlier detection is often contingent upon provider-initiated opportunistic screening, or upon women being aware enough of breast cancer symptoms and risk factors to seek timely examinations. However, based on the team's Risk Awareness Survey, knowledge about risk factors among women is limited. In a convenience sample of 16 women (with a median age of 26.5) surveyed on their awareness of breast cancer, results were promising. For example, over 65 percent of women recognized that a family history of breast cancer increased their risk. However, few to none linked lifestyle factors such as smoking, not bearing children, or obesity with increased risk. Providers also note that there is an overall lack of awareness regarding self-breast exams (SBE). Without widespread awareness of breast cancer, its risk factors, and SBEs, women may underutilize existing screening opportunities, ultimately rendering it less successful.<sup>26</sup>

Awareness pushes during breast cancer awareness month in October have been successful in the past lending support to the idea that lack of awareness is barrier that has been overcome by women in some parts of Kosovo. For example, when the mobile mammogram machine was stationed briefly in the Gjilan FMC, there was significant demand. There was a significant influx of women, made aware of the opportunity to have a mammogram. It took more than two days, but everyone who wanted a mammogram got one.

#### STIGMA

Primary and secondary care providers report that stigma is perceived as a barrier to screening because, as with lack of awareness, it prevents women from seeking care when appropriate, preventing earlier diagnoses. Providers consider this stigma to stem from the fear of diagnosis, rather than fear of the effects of breast cancer treatment.

Providers also share that there can be a stigma and/or fear associated with the screening methods themselves. Among older populations in Kosovo who will likely fall within the screening age bracket, there exists a culture of modesty and a related sense of discomfort toward the semi-nudity required when performing breast cancer screenings and examinations. In Gjilan, providers perceive that stigma is related to patients' age and level of education, but they remain optimistic that there will be a reduction in stigma as Kosovo's young population ages. Stigma can prevent women from seeking out screenings or opting to get screenings when they are offered to them resulting in delays to diagnosis and treatment.

## PROVIDER-SIDE

### **LACK OF UNIFORM INFRASTRUCTURE**

The team found that the lack of infrastructure poses a barrier to screening, because the required machinery is often nonfunctional, outdated, or lacking. Nonfunctional infrastructure is often the result of poor to no infrastructural upkeep. This section details two specific examples of infrastructural barriers. First, the regional hospital in Gjilan has a mammogram machine; however, this analog machine is now outdated and no longer in use. Without a mammogram machine at the MFMC in Gjilan, the region as a whole is unable to do screening via mammography because there is no mammogram machine at the primary- or secondary- levels. Second, a mammogram machine was donated to the MFMC in Lipjan. However, this machine has since broken and, because it was a gift, there is no current means of repairing the specific broken part.

Accordingly, resources are not uniform across facilities of different healthcare levels or regions of Kosovo. While some regional hospitals or MFMCs have functioning digital mammogram machines, others are lacking. While some machines are fully digital, others are analog and sometimes out-of-date and nonfunctional. On Page 13, a table outlines where mammogram machines are located at their respective level of the healthcare system.

Uniform infrastructure development is important because the efficacy of a screening program depends on the ability to provide these services well. In adherence to Kosovo's decentralized health system, resources such as mammogram machines should be consistent across facilities of the same level in all regions of the country, or the current distribution of resources must be taken into consideration. Mandating the delivery of care, without investing in appropriate training and machinery may mean that there is significant disparity in the care that is available to women regionally at the primary- and secondary levels.

### **HUMAN RESOURCES**

Providers note that there is a lack of personnel with the appropriate training to carry out a breast cancer-screening program, which would rely upon mammograms, ultrasounds, and CBEs.



Among all interview sites, the team found that the MFMC in Prishtina and UCK were the only facilities where some nurses were trained to conduct a CBE. Additionally, nurses were noted to commonly perform CBEs in Prishtina alone.

Furthermore, the team found that radiologists often find their departments understaffed, particularly at the primary level. They note that this becomes an issue for diagnosing breast cancer because mammography machines, and other forms of radiology tests for the breast region, are difficult to read due to tissue density, which requires high levels of training. As a result, a second or third opinion is often needed for diagnosis. However, at the primary level, there is only one radiologist per facility. Although diagnosis does not occur at the primary level, the lack of radiologists creates wait times for screening and breast cancer detection at MFMCs.

## **LACK OF PATIENT ORGANIZATION**

A lack of patient organization is a systemic barrier across all three levels of the healthcare system, with the UCK director of oncology noting that the lack of organization is the most difficult issue that the healthcare system face in regards to breast cancer, along with the lack of a patient picture archiving and communication system (PACS). Many providers expressed that not knowing the demographics of their patient population limits their ability to organize their patient constituencies. For example, family history is a strong risk factor for breast cancer, but records are not always kept in a way that helps providers track that information. Not having a census of patients in a catchment area makes it difficult for providers to track their patients' care at different facilities or track follow-ups. Patient documentation is mostly on paper, but in some facilities is split between paper and electronic records, such as at the Prizren regional hospital. Without knowing which patients fall within the target population, inviting women to screenings becomes more difficult. Internal patient organization may not be a prerequisite to a successful organized screening program, but will make screening much more efficient.

## **COMMUNICATION BETWEEN LEVELS**

Throughout Kosovo, providers at all three levels of the healthcare system consistently state that communication and organizational issues between facilities pose a significant barrier to introducing a BC screening program. Resources are scattered, so some standardization is necessary to get patients screened efficiently.

Specifically, providers note the inefficiency of the existing paper referral system. The existing system by law, requires that patients have a referral letter from their primary-care doctor in order to access secondary- or tertiary-level care.<sup>27</sup> However, because this law is not widely enforced, patients often bypass primary care to seek care from specialists at the secondary or tertiary level, even though primary care facilities can often provide the same services. The existing system can lead to increased turnaround times for patients referred to other providers that can take anywhere from two to three days to two-to-three weeks. As a result, diagnoses can take up to a month, even in Prishtina where resources are available at all healthcare levels.

To improve communication between levels of the healthcare system and patient follow-ups, an electronic medical record (EMR) and informatics system has started to be incorporated into the Kosovar healthcare system with plans to develop it more extensively. However, the system currently only connects select primary and secondary facilities, with no method of electronic referrals or patient follow-up at the tertiary level in UCCK. For breast cancer diagnosis, which often requires communication and confirmation between multiple providers at different facilities, the existing EMR does not accommodate important breast-cancer related inputs, such as biopsy and lab procedures.

## **NO NATIONAL BREAST CANCER PLAN**

Providers at the primary and secondary level share that they believe a screening program can only be achieved if it comes from a national mandate with standardized guidelines. They note the need for a “top down” approach to organize a program in order to ensure that the program is standardized across each healthcare facility and thus most effective and broad reaching. To ensure the equity element of screening access (see Table 1), it will be important for a ministry-led approach. This means that MFMCs and FMCs will have some objectives set by the ministry, even if they do not have direct oversight. This will help the system step away from piecemeal prevention efforts, to one that improves access and is easier for women to navigate.

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## **OPPORTUNITIES**

The team identified three main *opportunities* for points of intervention where Kosovo may take steps toward introducing screening by expanding on existing platforms of success. Because each primary and secondary healthcare facility varies in resources, infrastructure, and protocols for its response to breast cancer, the team finds that these opportunities may be used throughout the existing health-system as a whole, rather than at a specific level.

### **EXPAND EXISTING AWARENESS EFFORTS**

Mammogram usage spikes during Breast Cancer Awareness Month in October and the effect often rolls over into the next month. During October, strong pushes to mobilize women to get screening services have been successful in the past. Because these awareness campaigns and education initiatives have been successful in the short-term, this adds support that the material is effective. Therefore, using those materials and methods of communication outside of October may support women to come forward and ask for mammograms throughout the year. Other ways to leverage the calendar year for screening awareness may be to use holidays like Mother’s Day or Women’s Day to prioritize awareness campaigns in addition to the month of October.

Partnerships with the community have been successful in raising awareness for breast cancer and breast cancer screening. In Ferizaj, women were able to come to the clinic during awareness month and receive lectures on the consequences of breast cancer. These presentations were also offered at local schools and at institutions with more than 50 workers. There were also concurrent media campaigns to reinforce the idea of a routine checkup. Similarly, NGOs in Lipjan helped raise

awareness through media campaigns. Much of this informative material is focused on increasing mammogram use, but there is more education needed about self and clinical breast exams.

In Gjilan, school visits, office visits and media pushes have been effective in mobilizing more women to seek out screening services. The mobile mammography unit has helped women who have been exposed to awareness campaigns find an accessible destination for mammograms; whereas other primary and secondary facilities may not have working equipment and are generally overburdened.

## **LEVERAGE USE OF MOBILE MAMMOGRAPHY UNIT**

Kosovo has one digital mobile mammography unit that is currently located at UCCK. In the past, this unit has operated in various locations across the country to provide “mini-screening”-type services as part of the mobile mammography pilot project.

The unit is most active during October’s Breast Cancer Awareness Month. It currently fills in for non-functioning mammograms at health facilities, such as at Gjilan’s MFMC for a month in 2018, at Gjilan’s regional hospital in 2019, and at UCCK right now.

Along with providing mammography services in general, many providers have noted the role that the mobile unit has played to increase women’s awareness of breast cancer. In addition, the Ideas Partnership, an NGO that focuses on education, particularly within the Roma, Ashkali and Egyptian communities of Kosovo, perceives that the unit has improved both awareness and access to mammography for patients of these minority groups who cannot always afford the cost of MMG or associated transportation. If utilized more frequently, this mobile unit presents an opportunity to continue to increase accessibility to mammography to populations that otherwise may not have access and spread awareness throughout the country more generally.

## **TRAIN NURSES TO CONDUCT CBEs**

At most facilities visited by the team in Kosovo, if CBEs were performed, doctors were the only providers conducting them (e.g., family physicians, radiologists, or thoracic/general surgeons). However, at the Prishtina MFMC and UCCK, some nurses have gone through the necessary training to conduct CBEs, but do not usually provide them. Literature supports that training non-physician providers in conducting CBEs, and possibly educating patients about conducting self-breast exams, has led to an increase in the earlier detection of breast cancer in other lower resource settings.

Expanding nurses’ training and responsibilities to encompass CBEs, both in Prishtina and other regions, serves as a feasible way to increase the frequency of breast health examinations at all levels of the healthcare system, especially at primary care. Nurses can also raise awareness by educating women about SBEs and the symptoms of breast cancer so that patients become informed about seeking care earlier.

## **EXPAND USE OF RISK QUESTIONNAIRE**

The Prizren MFMC’s director of radiology has developed a questionnaire for the facility’s database in order to follow-up with female patients regarding breast health. This questionnaire could be

administered nationally and administered to assess breast cancer risk given the low prevalence of BRCA1/2 gene awareness in Kosovo. Other risk assessment tools such as the GAIL model, rely on understanding if the patient has previous experience with breast cancer, has a mutation in either the BRCA1/2 gene, and if family members have had breast cancer. A survey conducted by the team found that in a convenience sample of 16 women (with a median age of 26.5) many women did not know if they had the gene mutation, nor did anyone have a history of breast cancer in their family. This result may be attributed to lack of information about cancer care in the past.

The risk questionnaire used in Prizren incorporates many of the questions and topics of similar surveys used in Croatia and North Macedonia, and encompasses women's health history and risk factors, such as age of first menstruation, menopause, oral contraception, hormone replacement therapy, number of pregnancies and births, lactation, and family history of breast cancer. The second page details women's complaints or symptoms of any breast health abnormalities, such as benign cysts, calcifications, and fibroglandular tissue. In addition, the questionnaire collects information regarding most recent women's health-specific doctor's visits, and whether the patient previously had ultrasound or mammogram examinations done. The MFMC notes that the questionnaire allows them to track patients who have had ultrasounds and mammograms, and that this template could be used at the national level.

According to a 2018 assessment of GAIL-model performance for predicting breast cancer risk, "Gail model was appropriate for predicting the incidence of breast cancer in American and European women....it is still very valuable for women to have a well-calibrated risk assessment and select different prevention strategies that are suitable for their risk level."<sup>28</sup> The Prizren MFMC questionnaire, although different from the GAIL-model, could provide a strong base of knowledge until breast cancer-specific testing in the Kosovar population has increased significantly.

Table 4. Summary of system-wide barriers to introduce screening.

<h3 style="text-align: center;">Awareness</h3>	<h3 style="text-align: center;">Stigma</h3>
<ul style="list-style-type: none"> <li>• Screening is only <b>opportunistic</b></li> <li>• Women often <b>wait until BC symptoms are painful</b> before choosing to see a physician</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Fear</b> of BC diagnosis as a deterrent to get screened</li> <li>• <b>Discomfort</b> with screening procedures</li> </ul>
<h3 style="text-align: center;">Infrastructure</h3>	<h3 style="text-align: center;">Human Resources</h3>
<ul style="list-style-type: none"> <li>• Machinery required is often <b>nonfunctional, outdated, or lacking</b></li> <li>• Lack of <b>infrastructural upkeep</b></li> <li>• <b>Resources are not uniform</b> across facilities at the primary-level, at the secondary-level, or by district of Kosovo</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of <b>CBE training</b></li> <li>• Only <b>1 radiologist per MFMC</b></li> </ul>
<h3 style="text-align: center;">Patient Organization</h3>	<h3 style="text-align: center;">Communication Between Levels</h3>
<ul style="list-style-type: none"> <li>• Providers <b>lack a “list of patients”</b> within their district and standardized patient histories</li> <li>• Differences in paper vs electronic record keeping result in <b>tracking, follow-up, and patient referral difficulties</b></li> </ul>	<ul style="list-style-type: none"> <li>• <b>Difficulty in communication</b> between facilities of different healthcare levels</li> <li>• <b>Referral system is often bypassed</b> by patients seeking specialty care</li> </ul>
<h2 style="text-align: center;">No National Breast Cancer Plan</h2>	
<ul style="list-style-type: none"> <li>• Need for <b>national mandate</b></li> <li>• Need for <b>standardized guidelines</b></li> </ul>	

Table 5. Summary of opportunities to introduce screening.

<h3>Expand Existing Awareness Efforts</h3>
<ul style="list-style-type: none"><li>Based on the success of past awareness month campaigns, extending similar efforts yearlong may result in <b>greater awareness and utilization of breast health services</b></li></ul>
<h3>Increase Use of Mobile Mammography Unit</h3>
<ul style="list-style-type: none"><li>Increasing utilization of the mobile mammogram unit may <b>increase awareness and increase women's access to screening services</b></li></ul>
<h3>Train Nurses to Conduct CBEs</h3>
<ul style="list-style-type: none"><li>Nurses can be trained to <b>conduct CBEs</b> and <b>educate patients about SBEs</b> to increase likelihood of early detection and screening utilization</li></ul>
<h3>Expand Use of Risk Questionnaire</h3>
<ul style="list-style-type: none"><li>Expanding Prizren MFMC's patient questionnaire nationally could <b>increase risk assessment and track screening utilization</b></li></ul>

# POLICY OPTIONS

The team has tailored five policy options for Kosovo to build capacity towards creating a successful national organized screening program. These options are not designed to be carried out independently. Instead, Kosovo decision makers should work towards adopting multiple options in conjunction with one another to most effectively increase early breast cancer detection rates. Given the system-wide barriers identified previously, Kosovo could invest in building the health system's capacity to scale to a comprehensive, nationwide breast cancer-screening program. In the long term, implementing policy options as ministry financial allocation allows will ease the transition to a standardized breast cancer screening protocol.

Policy options are organized by their respective level of the healthcare system. Similar to previous pilot programs in Kosovo, such as the cervical cancer screening program and the mobile mammography unit, these options are designed to begin in centers of excellence in Prishtina and/or Prizren and to be expanded outwards, incorporating lessons learned. This may require either oversight, or incentives, because additional work for the same pay may become an issue.

## END-GOAL

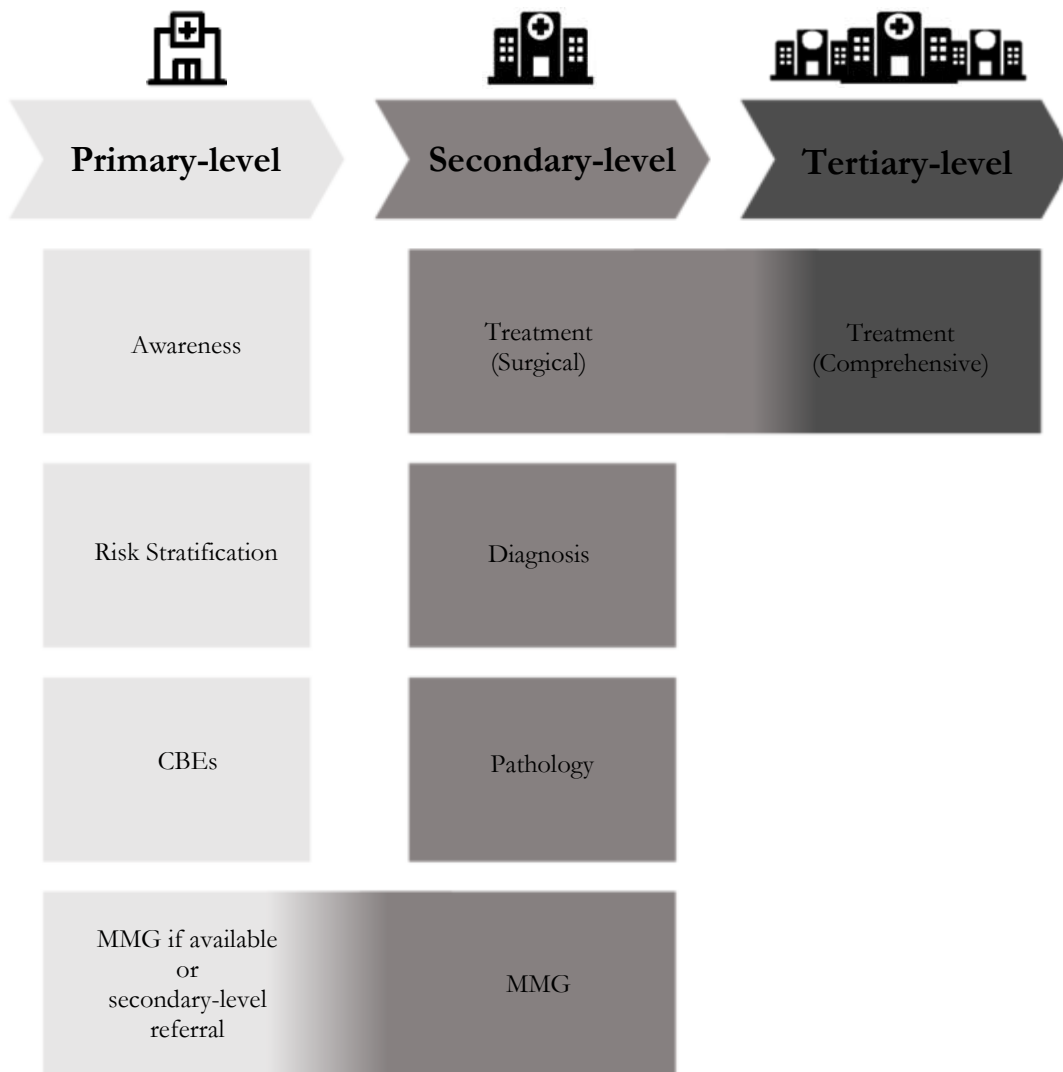
The team has designed policy options with the long-term goal of a national cancer policy to include screening. The European Commission Initiative on Breast Cancer's (ECIBC) Guidelines Development Group (GDG) recommends "using an organised mammography screening programme for early detection of breast cancer in asymptomatic women."<sup>29</sup> With this in mind, the team defines this end goal as a national breast cancer-screening program where women ages 50 to 69 would receive a biennial mammogram, in accordance with various cancer policies in EU countries.

The team has adapted this end-goal to be context-specific in Kosovo by taking into consideration the aforementioned barriers and opportunities. A national breast cancer-screening program could take place in Kosovo in the form of annual referrals from the primary-level to get screened at the secondary-level, or at primary-level facilities with adequate resources.

Primary-level facilities have the most patient contact and thus the greatest knowledge of patient constituency. As a result, primary-level facilities can best identify and invite at-risk target populations for screening services. Family physicians can then refer women to their district's regional hospital for screening instead. In the case that the primary-level facility has adequate resources for screening and trained staff, mammograms may be offered in MFMCs; however, few MFMCs currently have mammography machines. This pathway of care from breast cancer screening to diagnosis is displayed in Figure 3.

However, with the aforementioned barriers and opportunities in mind, the team details healthcare system level-specific policy options to support Kosovo’s efforts to introduce a screening program into the existing system.

**Figure 3. Summary of end-goal.** Proposed responsibilities organized by respective level of the healthcare system. Gradients refer to multidisciplinary, shared responsibilities that will benefit from increased communication between levels.





## PRIMARY-LEVEL OPTIONS

The goal at primary level is to develop capacity so that they can provide mammograms on-site if resources are available, or refer patients to their district's regional hospital. then, it is important to improve early detection through CBEs. Primary-level physicians should have a greater sense of their patient constituencies, so they may be best suited for sending invitations, for invitation-based screening. Options to facilitate this transition include:

### **AWARENESS AND EDUCATION**

According to the World Health Organization, “awareness is the first step in battle against breast cancer.”<sup>30</sup> Given lack of awareness as a barrier and expanding breast cancer awareness month as an opportunity discussed earlier, Kosovo has already taken strides to increase BC awareness in important and successful ways; however, given the importance placed on the BC awareness by the WHO, it is crucial that awareness campaigns continue to educate on symptoms, risk factors, and screening in order to detected BC earlier.<sup>31</sup> Specifically, building awareness of screening opportunities is crucial to increase participation in a screening program in itself because the “effectiveness of population-based screening programs substantially depends on participation.”<sup>32</sup> Primary care providers consistently reported that stigma is reducing as education and awareness efforts have increased.

### **INCREASE CBE FREQUENCY AT PRIMARY-LEVEL**

In the absence of mammography, a screening method that is often limited due to resource constraints, a higher number of cases of breast cancer can be detected using clinical breast exams (CBEs). Specifically, in India, it was determined that annual CBEs for women between ages 40 and 60 was nearly as successful for reducing breast cancer mortality as biennial mammography screenings, while only being half as expensive.<sup>33</sup> CBE in lieu of mammography has been a successful approach in Ghana as well, where breast cancer control is similar to that in Kosovo in that awareness is generally low and cases are often detected at late stages. Using a mathematical model to estimate cost and health effects of various breast cancer prevention, it was determined that biennial CBEs in women between the ages of 40 and 69, in conjunction with post-detection treatment, led to the most cost-effective intervention process, as opposed to mammography screening of women in the same age range, which was not considered cost-effective.<sup>34</sup>

CBEs are found to be an effective mode of cancer detection in regions constrained specifically by a lack of healthcare professionals as well. In rural regions of Jakarta, Indonesia, CBEs conducted by trained nurse midwives were “nearly as effective as mammography in detecting prevalent breast cancers.”<sup>35</sup> The approach of training healthcare providers of all levels at performing breast examinations was again seen in Rwanda, where health workers educated on the signs and symptoms of the disease saw a greater impact on earlier breast cancer detection.<sup>36</sup>

In Kosovo, introducing and expanding CBE access at the primary-level can help improve detection of breast cancer at earlier stages. As machinery and radiologists availability improves, these facilities can switch to providing more mammograms. Interviews with providers show that at the primary care level, they feel that they “do not diagnose, just suppose” given resource constraints. The introduction of CBEs may offer an alternative until mammograms are available widely at the primary level.

## **SMS TEXTS TO INCREASE PATIENT PARTICIPATION AND RETENTION**

Given that screening resources are not currently uniform throughout the country and, as a result, patients may not be invited by their providers, it is important that women are made aware that screening is an option where they currently seek care. SMS texts and reminders could function as the invitation needed to make more patients aware of screening opportunities.

Based on comparative case studies in low resource settings as well as success in Gjilan with text reminders for TB treatment adherence, there is an opportunity to leverage the high precedence of cell phone use in Kosovo to use SMS texts to increase patient participation and patient retention in Mammogram screening and follow up. Culturally-specific messages have shown higher rates of follow-up and offer an opportunity to address issues of stigma and shame specific to the Kosovar population. Randomized control trials have continued to find that SMS messages for breast cancer screening are beneficial for increasing participation by up to 5.5 percent.<sup>37</sup>

In Catalonia, Spain, the use of text-message reminders to improve breast cancer screening participation was found to be an efficient and cost-effective method, especially among “difficult-to-reach populations.”<sup>38</sup> The study found that, not only did patient participation in the screening program increase, but the effect was “even larger among women who [had] not previously participated in the screening program,” and “in that case, SMS reminders more than double[d] the likelihood to participate.”<sup>39</sup> Seeing as these SMS reminders were particularly successful among patients who had not participated in prior screening programs, this method could be effective in Kosovo where there is currently no organized screening program.

In addition, the use of SMS messages is not unique to reminding individuals to seek care/adhere to treatments. In western Kenya, text messages were used to communicate cervical cancer screening results to patients.<sup>40</sup> In a cluster-randomized trial, receiving results through text messages proved to be popular among younger populations. This faster, technology-based communication method could be a potential solution in Kosovo, where the median age is 29.6<sup>41</sup> and likely well-versed in technology. This may help mitigate some delays in breast cancer screening to treatment that are experienced across Kosovo. In addition, as this population ages and the disease burden increases, cell phones as a way to remind patients of biennial mammograms may be a strong lever for education, awareness and receptivity for screening because it is a generation intimately familiar with technology.

## **RISK-STRATIFICATION**

Successful screening programs require the establishment of a target population based on specific parameters, including age, family history, and other risk factors. Using these risk factors, a target population can then be stratified based on risk in order to prescribe specific methods of screening. Utilizing a risk stratification method to organize invitations for more frequent screening for higher-risk women could be done at the primary-level, where providers say they both have the most contact with patients, and are the first and last points of contact with patients as they enter and exit the healthcare system.

A study from Montreal, Canada, evaluating healthcare providers' views on risk stratification in breast cancer screening offers a twofold, stepwise approach to screening:

Step I: Assess risk level for disease to “choose and recommend proper screening” and stratify into groups according to risk level

Step II: Screen patients for the disease with the ultimate goal of early detection<sup>42</sup>

The GAIL-Model is an effective tool for risk-stratification specifically among American and European populations.<sup>43</sup> However, awareness of BC risk factors among Kosovar women needs to increase before this specific model can be used. As Kosovo works toward a national organized screening program, a combination of utilizing the existing Prizren risk questionnaire with modified GAIL-model risk assessment questions could prove useful for selecting suitable screening strategies based on women's risk level.<sup>44</sup>

## **SECONDARY-LEVEL OPTIONS**

The goal at the secondary-level is to provide mammograms on-site for patients referred from FMCs. Regional hospitals at the secondary-level of the health system will need to confirm diagnoses of breast cancer through mammograms, on the referral of FMC doctors as well. Options to facilitate this process include:

### **MOBILE MAMMOGRAPHY UNIT**

Based on providers' perceptions of the past success of the mobile mammography unit in raising breast cancer awareness and increasing mammography access, continued use of the mobile mammography unit could be beneficial throughout Kosovo.

According to the radiology department at UCCK, the mobile unit is currently located at UCCK to take the place of a currently nonfunctional mammogram machine. When this unit is no longer needed at UCCK, it could be further utilized in other regions of Kosovo where mammograms are nonfunctional/nonexistent. Providers in Gjilan noted the advantage of having the mobile unit for approximately one month per year for the past two years, at either the regional hospital or the MFMC.

This same tactic may be employed at other facilities around the country. However, like other screening infrastructure, providers note the importance of adequate maintenance and staffing of the mobile unit, if this is to be feasible.

This mobile unit could simultaneously function to increase access to screening and early detection among disadvantaged communities in Kosovo. According to the list of criteria for introducing a screening program from the WHO, a screening program “should promote equity and access to screening for the entire target population.”<sup>45</sup> The Ideas Partnership NGO notes how the machine has improved both awareness and access to mammography for patients of these minority groups who cannot always afford the cost of MMG in the private sector or associated transportation. If utilized more frequently, this mobile unit presents an opportunity to continue to increase accessibility to mammography to populations that otherwise may not have access and spread awareness throughout the country more generally.

# CONSIDERATIONS

In this section, the team offers a series of considerations for bolstering the success of an organized screening program in the long-term. These suggestions may also be used in conjunction with the policy options detailed above in order to extend their efficacy in increasing early breast cancer detection in Kosovo.

The policy options above were designed to bring Kosovo closer to the end goal of a national screening program, in which women ages 50 to 69 would receive a biennial mammogram, in accordance with various cancer policies in EU countries. However, as Kosovo builds capacity towards reaching this goal, Kosovo could define their own end goal to ensure that this screening program is most effective for its population. In this section, the team provides considerations for how Kosovo can design its own program to be tailored to its own needs and resources.

## DELIVERY OF SCREENING SERVICES

Breast cancer screening targets women who are asymptomatic and therefore have no immediate need to visit a doctor.<sup>46</sup> As a result, barriers that prevent women from attending screening opportunities will only function to reduce screening participation and cost-effectiveness of the program.<sup>47</sup>

Building upon findings from *Implementing Cervical Screening in Prishtina, Kosovo: Policy Recommendations for the Prishtina Municipality*, the team has adapted some of the reports' key priorities for making a screening program successful among Kosovar women. The characteristics include having screening be:

- “Easily accessible,
- Comfortable and appealing,
- Respectful of women’s privacy and confidentiality
- Free of charge (for *all* services from taking the screening test to the treatment of any disease that is identified).”<sup>48</sup>

Preventative care is difficult for overburdened women to seek out and for overburdened health systems to prioritize. However, to see the cost savings and health benefits these programs promise, it is essential to design them to be as efficacious as possible.

## TARGET POPULATION

For an organized screening program, a target population needs to be defined. The ECIBC’s Guidelines Development Group (GDG) recommends that screening programs are designed for women who are asymptomatic, and are not at high risk for breast cancer. Specifically, the GDG recommends screening women of ages 45-49 every two to three years, ages 50-69 biennially, and ages 70-74 triennially.<sup>49</sup> However, data on defining target populations is mixed and “target populations differ both between and within countries mainly depending on: breast cancer burden and life expectancy; sensitivity and specificity of mammography; socioeconomic and educational level.”<sup>50</sup> Table 6 details various recommended target ages ranges of various EU breast cancer screening programs.

**Table 6. Recommended target age ranges of various European breast cancer-screening programs.** All of the programs recommend screening with a frequency of two-year intervals, with the exception of the UK which recommends every year.

Countries	Age Range (Years)							
	40-44	45-49	50-54	55-59	60-64	65-69	70-74	≥75
Austria <sup>51</sup>								
Belgium <sup>52</sup>								
Denmark <sup>53</sup>								
Estonia <sup>54</sup>								
Finland <sup>55</sup>								
France <sup>56</sup>								
Germany <sup>57</sup>								
Hungary <sup>58</sup>								
Italy <sup>59</sup>								
Slovenia <sup>60</sup>								
UK <sup>61</sup>								

Providers at the tertiary-level note that, because Kosovo has a number of younger BC cases, a screening program beginning at age 40 may be effective. However, without a national cancer registry, robust age-stratified incidence data in Kosovo is not available such that an evidence-based recommendation on the age range cannot be decided upon at this time.<sup>62</sup> Therefore, as Kosovo introduces elements toward introducing a national screening program, evaluating screening success within its own population will be key because, if more cases of BC are detected, the target population may need to change to reflect that.

## RECRUITMENT OF WOMEN

Along with designating a target population and designing delivery of screening services, it is important to consider methods for recruiting women for screening, given that the “effectiveness of population-based screening programs substantially depends on participation.”<sup>63</sup> In order to extend mammography screening services to as many women within the defined target population as possible, decision makers may consider having secondary-level regional hospitals across Kosovo organize an invitation-based screening program in line with the invitation strategies of other population-based cancer screening programs in the EU.

For inviting asymptomatic women aged 50-69 to take part in BC screening, the ECIBC’s Guidelines Development Group (GDG) suggests using an invitation letter “with the general practitioner’s signature,” “with a fixed appointment,” “followed by a phone number” and/or “followed by a written reminder.”<sup>64</sup> The GDG has also developed recommendations electronically and suggests “using a letter plus SMS notification or an automated phone call plus a letter.”<sup>65</sup>

The team acknowledges that certain limitations apply to the Kosovo context, such as the lack of a patient informatics system/database/list of patients as well as lack of fully functioning digital mammogram machines at every hospital. However, as Kosovo builds capacity toward a screening program, invitation-based screening could elevate the number of women accessing breast health services annually as well as increase earlier detection.

Decision makers may also consider a prior report titled, *Implementing Cervical Screening in Prishtina, Kosovo: Policy Recommendations for the Prishtina Municipality*.<sup>66</sup> The report recommends recruiting women by undertaking (1) telephone invitations of disadvantaged women registered with the Department of Social Welfare, (2) referrals from family doctor referrals, and (3) a promotional campaign.

# CONCLUSION

As the burden of late-stage breast cancer continues to rise in Kosovo, this study aims to understand the current limitations of pathways to breast cancer diagnosis in country and to explore policy options for transitioning to a national screening program. The current conditions of the three-tiered health care system in Kosovo pose a series of patient- and provider-side barriers to the quick development of an efficacious screening program without investment. The barriers include limited awareness, stigma, healthcare system communication and organization, and limitations with machine and human resources. Opportunities to integrate a standardized breast cancer-screening program include expanding current awareness programs, standardizing breast cancer risk assessment at the primary care level, and training providers to conduct CBEs.

As Kosovo continues to develop and the needs of the population evolve, building healthcare system capacity to achieve a national screening program will require prioritization and investment in breast cancer prevention policy options. Kosovo decision makers should work towards adopting multiple options in conjunction with one another to most effectively increase early breast cancer detection rates.

As the burden of late-stage breast cancer continues to rise in Kosovo, this study aims to understand the current limitations of pathways to breast cancer diagnosis in country and to explore policy options for transitioning to a national screening program. The current conditions of the three-tiered health care system in Kosovo pose a series of patient- and provider-side barriers to the quick development of an efficacious screening program without investment. The barriers include limited awareness, stigma, healthcare system communication and organization, and limitations with machine and human resources. Opportunities to integrate a standardized breast cancer-screening program include expanding current awareness programs, standardizing breast cancer risk assessment at the primary care level, and training providers to conduct CBEs.

As Kosovo continues to develop and the needs of the population evolve, building healthcare system capacity to achieve a national screening program will require prioritization and investment in breast cancer prevention policy options. Kosovo decision makers should work towards adopting multiple options in conjunction with one another to most effectively increase early breast cancer detection rates.



# APPENDIX

## APPENDIX A – Risk Awareness Survey

1. What is your age?  
\_\_\_\_\_ years
2. What is your birth year?  
\_\_\_\_\_
3. What is your occupation?  
\_\_\_\_\_
4. What is your highest level of education completed? If currently enrolled, highest degree received.
  - Low secondary school
  - High secondary school
  - Some college completed, no degree
  - Associate degree
  - Bachelor's degree
  - Master's degree
  - Professional degree
  - Doctorate
5. What do you think are the risk factors for breast cancer? Check all that apply.
  - Family history of breast cancer in a grandmother
  - Family history of breast cancer in a mother or sister
  - An uncle with breast cancer
  - Late child-bearing
  - No child-bearing
  - Early menses
  - Birth control
  - Abortion or miscarriage
  - Obesity
  - Smoking
  - Alcohol use
6. Do you have a medical history of any breast cancer or ductal carcinoma in situ (DCIS) or lobular carcinoma in situ (LCIS)?
  - Yes
  - No
  - I don't know

7. Have you received previous radiation therapy to the chest for any reason or for treatment of Hodgkin lymphoma?
- Yes  
 No  
 I don't know
8. Do you have an inherited mutation in either the *BRC A1* or *BRC A2* gene, or a diagnosis of a genetic syndrome that may be associated with elevated risk of breast cancer?
- Yes  
 No  
 I don't know
9. Have you ever had a breast biopsy?
- Yes  
 No  
 I don't know
- If yes, how many breast biopsies (positive or negative) have you had?
- 1  
 2 or more
10. Have you ever had a breast biopsy with atypical hyperplasia?
- Yes  
 No  
 I don't know
11. What was your age at the time of your first menstrual period?
- 7 to 11  
 12 to 13  
 14 or older
12. Have you gone through menopause?
- Yes  
 No  
 I don't know
13. Have you given birth to a child?
- Yes  
 No
- If yes, what was your age when you gave birth to her first child?
- \_\_\_\_\_ years

14. How many of your first-degree relatives (mother, sisters, daughters) have had breast cancer?

- None
- One
- More than one
- I don't know

15. Have you ever felt a lump in your breast?

- Yes
- No

→ If yes, what did you do?

## APPENDIX B – Resource Capacity Survey

### Ultrasounds

1. Are there ultrasounds in this facility? If yes, how many?

- Yes: \_\_\_\_\_
- No
- I don't know

2. Are these ultrasound machines in good condition?

- Yes
- No
- I don't know

3. How often are these ultrasound machines used for breast imaging?

- Daily or more
- Weekly
- Monthly or less
- I don't know

4. Which professionals **are trained** to operate ultrasound machines? Check all that apply.

- Doctors
- Nurses
- Radiologists
- Technicians
- Other: \_\_\_\_\_

5. Which professionals **most commonly operate** ultrasound machines? Check all that apply.

- Doctors
- Nurses
- Radiologists
- Technicians
- Other: \_\_\_\_\_

## Mammograms

6. Are there mammogram machines in the facility? If yes, how many?
  - Yes: \_\_\_\_\_
  - No
  - I don't know
  
7. Are these mammogram machines in good condition?
  - Yes
  - No
  - I don't know
  
8. How often are these mammogram machines used?
  - Daily or more
  - Weekly
  - Monthly or less
  - I don't know
  
9. Which professionals **are trained** to operate mammogram machines? Check all that apply.
  - Doctors
  - Nurses
  - Radiologists
  - Technicians
  - Other: \_\_\_\_\_
  
10. Which professionals are **most commonly operate** mammogram machines? Check all that apply.
  - Doctors
  - Nurses
  - Radiologists
  - Technicians
  - Other: \_\_\_\_\_

## Clinical Breast Exams

11. Does this facility conduct clinical breast exams?
  - Yes
  - No
  - I don't know
  
12. Which professionals **are trained** to conduct clinical breast exams? Check all that apply.
  - Doctors
  - Nurses
  - Radiologists
  - Technicians
  - Other: \_\_\_\_\_

13. Which professionals **most commonly conduct** clinical breast exams? Check all that apply.

- Doctors
- Nurses
- Radiologists
- Technicians
- Other: \_\_\_\_\_

14. How often are clinical breast exams given?

- Daily or more
- Weekly
- Monthly or less

#### **Risk Assessment**

15. Does this facility use a breast cancer risk assessment tool?

- Yes → If so, which (e.g. GAIL-Model)? \_\_\_\_\_
- No
- I don't know

#### **Human Resources**

16. How many **physicians** work at this facility? \_\_\_\_\_

17. How many **nurses** work at this facility? \_\_\_\_\_

18. How many **radiologists** work at this facility? \_\_\_\_\_

19. How many **technicians** work at this facility? \_\_\_\_\_

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