

**Susan G. Komen for the Cure® Global Initiative for
Breast Cancer Awareness**

UKRAINE

Community Profile Executive Summary and References

**Kyiv
Lviv
Odesa**

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The information contained in this Community Profile has been compiled by Course for the Cure™ participants and comes from a variety of sources. Participants have attempted to obtain the latest and most reliable data available and to accurately reflect breast cancer challenges and resources in their city at the time of the profile. Susan G. Komen for the Cure does not recommend, endorse or make any representations or warranties of any kind with respect to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of the information contained in this summary.

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Executive Summary

Introduction of Susan G. Komen for the Cure Global Initiative for Breast Cancer Awareness

An estimated 25 million women around the world will be diagnosed with breast cancer over the next 25 years, and up to 10 million could die without a cure. With this in mind, Susan G. Komen for the Cure® - the world's largest grassroots network of breast cancer survivors and activists - launched the Komen for the Cure Global Initiative for Breast Cancer Awareness. The Institute of International Education (IIE) - one of the world's most experienced global higher education and professional exchange organizations - designed and manages the Initiative through its West Coast Center, in collaboration with local partners in eight pilot countries: Brazil, Costa Rica, Jordan, Mexico, Romania, Saudi Arabia, Ukraine and United Arab Emirates.

The goal of the Initiative is to create a dynamic global network of dedicated activists with the skills, knowledge and vision to play a strategic role in shaping their countries' response to breast cancer. This is accomplished by (1) empowering diverse stakeholders with the training, tools and support needed to influence strategic, locally-appropriate programming and funding decisions around breast cancer; and (2) strengthening individual and organizational capacity to launch effective education, awareness and advocacy campaigns to increase early breast cancer detection and reduce mortality.

At the core of the program is Course for the Cure™, a series of training modules based on Komen's 25 years of experience in breast cancer awareness and advocacy. The training modules, which have been customized in each country, cover five key topics: Community Assessment, Volunteer and Organization Development, Awareness and Education, Fundraising, and Advocacy.

Goal of the Community Profile

This Community Profile Report details the findings of Course for the Cure™ participants in Kyiv, Lviv and Odesa. The goal of the community profile is to assess breast health needs and resources, define the priorities and objectives for future action, and inform the work of breast health organizations and activists in their fight against breast cancer.

As part of the course's follow-up activities, participants have collaborated with Global Initiative staff to apply the community profile skills they are learning. Demographic, statistical, and program and service provider data – as well as data from formal and informal leaders in the community – are included to provide a multifaceted picture of breast health. After collecting and analyzing available data on breast health and services, participants identified and prioritized the community's current unmet needs or “gaps” in breast health. These prioritized gaps form the basis for developing plans for education outreach, awareness programs and advocacy efforts to improve breast health outcomes.

The Community Profile should be made widely available to the community and used on an on-going basis to inform strategic planning around breast health and to strengthen existing programs and services. As a living document, it also needs to be updated on a regular basis as circumstances change and new information becomes available.

Country Context Overview

Between early 1993, when Ukraine registered its greatest size of population (52,244,100 people), and early 2008 (46,372,700 people), the natural population loss alongside negative migration balance resulted in Ukraine's population declining by 5,871,400 persons. The major causes of depopulation were a 40 percent decline in birth rate over the period and a rise in death rate by nearly 30 per cent. As of 1 January 2008, the urban and rural population in absolute figures amounts to 31,668,800 and 14,703,900 respectively. Average life expectancy is 63.2 years for men and 73.8 for women. Women account for 54 percent of Ukraine's population. The proportion of female population significantly exceeded the male in the older age groups, with twice as many women as men in the 65+ age group.

Breast cancer has occupied the first place in the pattern of malignant neoplasms in Ukrainian women over the past 16 years, and the situation remains stable from year to year. The highest level is registered at ages between 45 and 65 (over 50% of all cases). Breast cancer incidence per 100,000 women increased from 22.6 in 1986 to 56.1 in 2005. About 27.6% of cases are diagnosed in advanced stages (III-IV).

The highest breast cancer disease incidence has been registered in the Odesa Region, Kharkiv Region, Dnipropetrovsk Region, the Autonomous Republic of Crimea – all listed regions are situated in the south and east of Ukraine - and in the cities of Kyiv and Sevastopol. Breast cancer morbidity rates in regions affected by the Chernobyl accident (Chernihiv Region, Zhytomyr Region, Kyiv Region and Rivne Region) does not exceed Ukraine's average but has tended to gradually increase during last 20 years.

In analyzing Ukraine's morbidity pattern, it should be noted that about 27.6% of cases are diagnosed in advanced stages (III-IV). The National Cancer Registry lumps data on cases in stages I and II together, making it impossible to precisely determine the number of cases detected in the earliest stage.

The rate of breast cancer mortality was registered in year 2006 as 17.5 per 100,000 of women population, and 7,607 women died of breast cancer in 2006. Starting from age 30, breast cancer is number one in the pattern of mortality caused by malignant neoplasms.

The highest levels of breast cancer mortality can be seen in Odesa Region, Kharkiv Region, Dnipropetrovsk Region, the Autonomous Republic of Crimea and Kyiv City.

Breast cancer diagnostics in Ukraine

The public healthcare system has been unchanged since Soviet times. General distinctive features of the public healthcare system in Ukraine are as follows:

- state ownership of health care institutions and establishments (private ones do not exceed 5% and are practically absent in oncology);
- the system of funds distribution and sector management in a “top down” structure;
- nontransparent, limited funding with the population paying illegally for services with no quality guarantee;

- insurance system of health care is not introduced for the minority of the population of Ukraine.

Breast pathology is identified at the level of primary care providers, including: village first-aid stations in rural areas and exam rooms at polyclinics, maternity welfare centers, family doctors' clinics, general-purpose polyclinics and others in (rural) district centers and towns. Oncological dispensaries (centers) are specialized medical institutions providing final diagnostics and breast cancer treatment. As a rule there is one such dispensary per regional centre and region. Kyiv and other big cities (with more than 1 million residents) have one dispensary for the city and one for the region. The Kyiv-based Institute of Cancer of the Academy of Sciences of Ukraine is the leading specialized medical institution.

Major methods to diagnose breast diseases are mammography, clinical examination of breasts, ultrasound investigation and self-examination of breasts.

Starting in 2001, civil society organizations and state-run healthcare institutions stepped up efforts to purchase diagnostic equipment (mammographs and mammogram developing machines) and mount information campaigns to make women aware of the need for screening breast examination in particular by mammography.

CBE is supposed to be carried out by medical personnel, obstetricians of village first-aid stations (feldshersko-akusherskyy punkt), medical assistants, district therapists, obstetricians of maternity welfare centers, family doctors, surgeons and oncologist surgeons. According to statistical data of the Ministry of Health of Ukraine, Department of Woman and Child Health Care, 2004 the percentage of breast cancer detection by clinical breast examination varies from 18% to 40.9% in different regions of Ukraine.

Community Profile Findings - Kyiv

Demographic Findings

Kyiv, the capital of Ukraine, founded in 482 AD, is located in the northern part of the country. Its area totals 825 sq km. the city's population is 2,740,200 persons. Kyiv's female and male population account for 53 and 47 per cent respectively. More than half of women are in registered or unregistered marriage (data are not divided by age). Kyiv's female population breaks down into the following age groups: 35.8% are aged under 30, 14.4% are between 30 and 39, 22.9% between 40 and 54, and 25.4% are 55 or older.

The educational level of women living in Kyiv is high. Women are not only engaged in services (as the case is in most regions of Ukraine) but also occupy managerial positions.

Breast Cancer Statistics

According to Kyiv City Oncological Hospital data (2007), breast cancer occupies the third place in Kyiv (17.5 cases per 100,000 persons) after lung and stomach cancers in the pattern of mortality caused by malignant neoplasms.

An average of 1,172 women is diagnosed with breast cancer in Kyiv every year. Women over 55 have the highest rate of breast cancer incidence among the Kyiv population. Women in the 40-54 age bracket also feature a relatively high morbidity rate. On average, stages I-II account for approximately 68% of cancers detected every year and stages III-IV for 32% of all cases.

Mortality rate among women with breast cancer increases with every passing year – in 2004 it was 29.0, in 2005 – 32.4 and in 2006 – 35.9. The largest number of mortality cases is in the 55+ age category.

Programs and Services

Breast cancer can be diagnosed during women's annual examinations by OB/GYNs, family doctors, or midwives in the rural areas.

Women who reside in Kyiv and have officially registered their Kyiv residence with local authorities can apply for medical assistance on a free basis, but only if they have been referred to the above organizations by a family doctor or a physician at a primary level medical institution. In Kyiv, mammography is available at 6 state medical institutions. Private clinics charge \$50 to \$200 for a mammography screening. Ultrasonic diagnosis apparatus are available in nearly every hospital and in many small private clinics but are not considered by the oncologists as a separate research method that could substantially impact the diagnosis of oncological diseases in Kyiv.

Awareness raising and educational campaigns are carried out thanks to the efforts of NGOs in collaboration with corporate businesses. Financing of breast health educational programs from the state budget was declared in the National Oncology 2002-2006 program but in fact has never been executed. In 2004, 20 October was declared as All-Ukrainian Day of the Fight Against Breast Cancer.

Identified and Prioritized Gaps

Problems and gaps identified by the participants, *after reviewing the community profile data*, were the following, in order of priority:

1. Inadequate system of providing medical services for early detection of breast cancer
2. Low awareness of women about breast cancer and seriousness of disease
3. Legislative and human rights vulnerability of oncological patients

Strategic Goals and Objectives

The main goal is to improve medical services in early detection of breast cancer, decrease the number of advanced cancer cases and mortality from breast cancer and also to improve the quality of life of breast cancer patients.

Objectives:

1. Advocate at the city level for improving medical services for early detection of breast cancer
2. Raise awareness of women about breast cancer in Kyiv
3. Strengthen information and legislative support to oncological patients

Community Profile Findings - Lviv

Demographic Findings

The city of Lviv is the capital of the Lviv Region situated in the western part of Ukraine, bordering Poland. The population of the region is 2.6 million people; its area is 21,800 sq. km. Lviv was founded in 1256 and is now home to 754,713 permanent residents.

Lviv and the Lviv Region are mostly populated by Ukrainians, who constitute about 70%. The ethnic minorities include Polish, Russian, Hungarian, Jewish, Armenian, Romanian, Roma and some others. Territorially, Lviv belongs to the region with a high rate of emigration.

The available demographic indicators are as follows: the expected age of the first marriage is 19-22 years on average; women have two children on average; the divorce rate for both men and women is lower than the average national indicator because of the strong influence of religion. The Lviv Region is under the strong influence of the Greek Catholic, the Rome Catholic and the Ukrainian Orthodox Churches. The official nominal average monthly pay in the Lviv Region is estimated at UAH 1,182 (about US \$244).

Breast Cancer Statistics

An average of 662 breast cancer cases are registered in Lviv every year. The disease most often occurs in women aged 55+. Cancer stages I-II account for an average of 69%, stage III for 16.5% and stage IV for 12%.

Mortality rate among women having breast cancer in Lviv has remained unchanged for the past few years – 25. (an average of 338 women annually). Mortality during one year after diagnosis is 13.0% (2007). An average of 51.2% of Lviv women live less than 5 years after cancer therapy.

Programs and Services

The Lviv Region has a developed network of medical institutions which have the necessary conditions for carrying out clinical breast examination (CBE). Such services are mainly provided by maternity welfare centers' doctors and midwives of the examination rooms of polyclinics. But CBE is still a problem because inadequate training of the medical personnel in correct and regular performance of CBE, time limitations for medical personnel to perform CBE and low women's motivation to undergo CBE.

In Lviv, mammography can be performed in four medical institutions. There is no organized program of population based mammography screening. Women only apply for mammography when they themselves find any changes in their breasts or when they have been referred by other medical providers/physicians. There is no strategy of developing screening in the region due to the absence of the technological base and lack of experience in organizing screening programs.

Campaigns raising breast cancer awareness are rather weak and are not carried out on a continuous basis, as was evidenced by the participants and key informants. Small-scale actions such as conferences, roundtables and presentations on local television and radio are performed every year in October, on the Day of Fighting Against Breast Cancer.

Informational fliers targeted at patients - which promote the importance of early detection - sporadically appear in medical institutions, but their quality and quantity do not correspond to the needs of women and do not motivate the readers to take action. A woman has no possibility to undergo breast examination on a free basis on her own initiative. At the minimum, a woman has to cover the cost of film used for examination herself.

Only six oncologists who specialize in breast cancer treatment work in the city. The local university does not train such specialists; therefore the city is in continuous need of skilled professionals.

Identified and Prioritized Gaps

Problems and gaps identified by the participants, in the order of priority include:

1. Women seem to be negatively biased and lack motivated to take part in the regular clinical screening services. This lack of motivation is the result of insufficient information about the effectiveness of this program and its positive results.
2. Low level of qualification of medical staff that provide women with clinical breast examination.
3. Limited accessibility of medical services (lack of the material and technical base, including mammography machines, and obsolescence of the available ultrasonic diagnosis apparatus).
4. Unsatisfactory financing of the state screening programs at all stages.

Strategic Goals and Objectives

The main goal is to inform women about the effectiveness of early detection of breast cancer and positive results of screening, to increase level of medical staff in order to provide women with high-quality services as well as widen accessibility to medical services.

Objectives:

1. Carrying out effective informational and educational campaigns for the population to overcome a biased attitude to screening and raise motivation
2. Increasing level of qualification of medical staff in polyclinics on clinical breast examination
3. Support to and development of advocacy at the regional and national levels

Community Profile Findings - Odesa

Demographic Findings

The city of Odesa is situated on the north-western coast of the Black Sea, on the crossroads of the routes from Northern and Central Europe to the Middle East and Asia. The city is populated with nearly one million people (982,920 citizens). The Odesa Region is one of the most ethnically diverse regions of Ukraine and altogether is inhabited by 38 ethnic minorities.

The city is overloaded with enterprises of the chemical, oil refining and construction industries. Odesa is also a port, one of the largest ports on the Black Sea, which greatly complicates the ecological situation in the city.

Odesa's female population (53.6%) breaks down into the following age groups: 32.6% are under 30; 14.7% between 30 and 39, 21.9% between 40 and 54 and 30.8% are 55 and older.

Odesa's female population breaks down into the following groups depending on their level of education: higher education - 43.2%, secondary education - 43.7%, primary education - 9.3% and uneducated – 3.8%.

More than half of the women are in a registered or unregistered marriage (data are not divided by age).

Breast Cancer Statistics

Odesa and the Odesa Region are among the leaders in Ukraine regarding the incidence of breast cancer. The mortality is also high.

An average of 958 new breast cancer cases are registered in Odesa every year (rates are not available). The most vulnerable category of Odesa's female population diagnosed with breast cancer is women in the 40-50+ age bracket.

Stages I-II account for an average 72% of cancers and stages III-IV for 28% of all cases detected annually.

Programs and Services

The majority of medical institutions provide clinical breast examination services. According to official documents, such an examination should consist of collection of anamnesis, identification of breast cancer risk factors and the examination proper (inspection and palpation). In case any changes are detected, patients are referred to the Odesa-based Regional Oncological Center where they undergo a more extensive examination including mammography, biopsy and the use of oncological markers. Services regarding surgical treatment of pre-tumor pathologies are provided by the Odesa-based Regional Clinic.

There are no programs of organized mammography screening in Odesa, though the city has six modern mammography units two of which are at the disposal of state-owned medical institutions and four are owned by other entities. The cost of examination is between US \$15 and \$60. Women cannot undergo **free** breast exams on their own initiative, only on reference by a doctor.

Women receive information about the importance of early detection from physicians (obstetricians-gynecologists, therapists, endocrinologists). Of late, medical institutions have posters (sanitation bulletins) and booklets on display, which are published at the expense of the local budget, but their quantity is very limited. During interviews, the key informants also mentioned the Internet and the press as the main sources of information outside medical institutions; mass information campaigns had not been conducted in Odesa. Meanwhile, lectures were traditionally delivered for doctors working at production enterprises and other establishments and consultations were provided on applying to medical institutions.

Identified and Prioritized Gaps

Problems and gaps identified by the participants based on this community profile research, in the order of priority, are:

1. Lack of information about the importance of early detection of breast cancer
2. Absence of clear information about the available resources in providing early diagnostic services.
3. Lack of motivation to take part in preventive examination programs due to:
 - fear of the disease;
 - mistrust of doctors and the system of medical assistance provision;
 - doubts about the successful outcome of treatment (pessimism);
4. Lack of mechanisms of financial provision of the entire process – from diagnosing to treating – at the expense of the state budget, and not at the expense of patients.

Strategic Goals and Objectives

The main goal is to increase early detection, to decrease mortality from breast cancer, to inform women about the importance of early detection of breast cancer, to motivate women to take part in preventive examination programs as well as encourage local officials to allocate money for a breast cancer screening program.

Objectives:

1. Raise the population's motivation to take part in preventive programs and transform the existing stereotypes about the disease and its course
2. Raise people's awareness about the breast cancer problems
3. Advocate for attracting new finance resources as well as for increasing and re-arranging financing from the city budget for preventive measures