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# Ukraine Breast Cancer Assistance Project

## Final Report

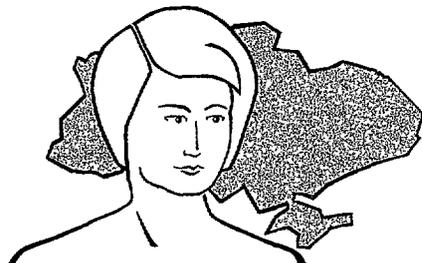
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Program for Appropriate Technology in Health

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## EXECUTIVE SUMMARY

From January 1997 through September 2000, PATH implemented a US\$3.8 million, USAID-funded project to strengthen breast cancer services in Ukraine. The Ukraine Breast Cancer Assistance Project had the following key goals:

- improving the quality of breast cancer services for screening, diagnosis, and treatment and rehabilitation;
- optimizing the utilization of these services among women at risk, especially among women exposed to radiation from the Chernobyl accident; and
- enhancing the cost-effectiveness of services within existing facilities and current resource constraints.

The general strategies for achieving these goals were:

- exchanging professional knowledge and skills;
- enhancing the availability of essential equipment and supplies;
- increasing patient understanding and public awareness of breast cancer;
- strengthening the health infrastructure; and
- refining relevant policies and practice guidelines.

PATH's Ukrainian partners in the project were breast cancer diagnosis and treatment centers in Kyiv, Chernihiv, Odesa, and Lviv and the Pathology and Oncology Departments of Lviv State Medical University.

The project team consisted of PATH staff and consultants based both in Seattle and in Kyiv.

The major program components included:

***Training for Health Care Providers.*** A variety of methods were employed to expose health workers to new ideas and techniques. These took place both within Ukraine and abroad, and included a U.S. study tour, fellowships, skills workshops, medical symposia, conferences, and medical literature dissemination.

***Provision of Equipment and Supplies.*** The following key pieces of equipment were supplied:

- four mammography units and film processors
- mammography film, chemicals, accessories
- one ultrasound machine
- pathology equipment (e.g., microscopes), reagents and supplies, hormone receptor test kits
- surgical equipment and supplies
- seven computers, two slide projectors, three fax machines, two VCR/TVs
- thirty courses of chemotherapy

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***Patient Understanding and Public Awareness.*** PATH developed and disseminated informational materials and facilitated public awareness campaigns to increase Ukrainians' understanding of breast cancer. This focus broadened later to encompass innovative and surprisingly successful survivor support and outreach programs.

***Strengthening the Health Infrastructure.*** PATH aided the National Cancer Registry in its efforts to upgrade by providing a computer and fax-modem, limited technical assistance, and subcontracts to support travel and assistance by central registry staff to oblast registry staff.

As part of the pilot breast cancer early detection program in Chernihiv, the local health information system was modified on a test basis to collect data on the outcome of clinical breast exams.

***Influencing Policies and Practice Guidelines.*** An important intention of the project was to help influence national and local policies and practice guidelines related to breast cancer in several areas.

Progress was achieved to varying degrees in the following selected policy or practice areas:

- demonstration of an early detection strategy in a pilot area using both clinical breast exam (CBE) and mammography;
- demonstration of an international standard-dose chemotherapy regimen through a clinical trial
- demonstration of the value of immunocytochemistry (ICC) methods for better pathology diagnosis;
- demonstration of the feasibility of survivor outreach and advocacy initiatives;
- assessment of radiotherapy capacity and recommendations for improvement; and
- modification of surgical approaches to breast cancer and benign breast disease.

***Cost-Share Contributions.*** PATH was able to leverage USAID funding by raising US\$413,354 in direct donations and in-kind contribution of goods and services from non-federal sources. This exceeded the required contribution (\$263,440) by 57 percent.

## **Lessons Learned**

***Clinical Care.*** Medical approaches from other areas should not be adopted without careful analysis of their appropriateness to the Ukrainian situation. Some of the reasons for the differences between clinical practices in Ukraine and those in the United States are discussed in the report. A team approach to clinical care is feasible and cost-effective within Ukraine. Effective clinical care depends upon the coordination of services including reliable pathology, appropriate surgical care, chemotherapy, and radiotherapy.

***Psychosocial Support.*** Most breast cancer patients want to be told their diagnosis. Although Ukrainian physicians still do not always tell patients that they have cancer, many patients know their diagnosis and want to communicate more openly with health care professionals about their disease. Working from that information, PATH was able to catalyze change promoting psychosocial support among breast cancer survivors by proceeding from a scientific basis, facilitating the efforts of the women themselves, and linking the survivors with established international groups.

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**Regional Links.** Links with neighboring countries in the region provide useful and relevant experience and knowledge. Ukrainians have developed contacts and growing connections with colleagues and volunteer partners from Poland, the Czech Republic, Russia, and Belarus. Encouragement of regional activities is strategically effective, because the people of the region have experienced common problems and organizational structures in recent history.

### **Follow-on Needs**

The following areas of need were identified during the project, and remain to be fully addressed as the project closed. They are discussed in detail further in the report.

- Medical Training and Education
- Equipment and Supplies
- Quality Control for Mammography, Radiotherapy, and Pathology
- Support for Maintaining Regional Linkages
- Training and Organizational Support for Survivor Groups

There are good reasons to believe that many of the project achievements described in this report are sustainable beyond the life of the project. For example:

- all the training activities of the project represented investments in *human capacities* that will last long after the project's end;
- health workers, patients, and the general public were all exposed to new ideas that will influence their perceptions and attitudes for years to come;
- specific *tools* such as the various curricula, learning aids, print and audiovisual materials, and equipment will remain in use and continue to provide benefit;
- the establishment of *institutional structures* like the breast cancer survivor groups that have registered as NGOs and the Early Detection working group, the strengthening of the cancer registries, and the development of the clinical-trials capacity in Odesa represent achievements that are embedded in Ukrainian structures that have a life of their own.

We feel strongly that the success of this project is due not only to the work of the entire PATH team and our Ukrainian partners, but to all the individual medical workers, patients, and community members in Ukraine who opened their minds to consider new possibilities and contributed their ideas and efforts toward our common goal of helping to reduce the impact of breast cancer on the women of Ukraine.

### **Benefits Beyond Breast Cancer**

In addition to the project's significant achievements in improving breast cancer care, many of the activities and practices introduced and encouraged by this project have attributes with immediate carry-over and relevance to other areas of Ukrainian health care.

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## OVERVIEW OF PROJECT

From January 1997 through September 2000, PATH implemented a US\$3.8 million, USAID-funded project to strengthen breast cancer services in Ukraine. The Ukraine Breast Cancer Assistance Project had the following key goals:

- improving the quality of breast cancer services for screening, diagnosis, treatment, and rehabilitation;
- optimizing the utilization of these services among women at risk, especially among women exposed to radiation from the Chernobyl accident; and
- enhancing the cost-effectiveness of services within existing facilities and current resource constraints.

The general strategies for achieving these goals were:

- exchanging professional knowledge and skills;
- enhancing the availability of essential equipment and supplies;
- increasing patient understanding and public awareness of breast cancer;
- strengthening the health infrastructure; and
- refining relevant policies and practice guidelines.

In support of each goal, different combinations of strategies were used. To improve screening, for example, all five strategies were employed: training in clinical breast exam and mammography, provision of critical equipment, public awareness campaigns, strengthening of the cancer registry and other data monitoring systems, and development of position papers and special meetings. In the area of diagnosis, provider training in breast imaging modalities and special pathology techniques, along with provision of equipment and supplies, were the main strategies. To improve treatment, the project strengthened professional knowledge by updating the general thinking about the pathobiology of breast cancer, modeling the multidisciplinary team approach to treatment and familiarizing providers with issues and tools related to psychosocial support of patients. The project developed specific print materials for patients to help them understand treatment procedures. Rehabilitation efforts were focused on building psychosocial support systems for patients, and involved establishing formal peer support and outreach groups, developing informational materials, organizing a series of meetings and exchanges, and preparing a policy paper. Cost-effectiveness was a consideration in the teaching methods chosen, in the type of equipment and supplies provided, in the infrastructure improvements proposed, and in several of the policy papers that were written.

PATH's three original partners in the project were:

- The Ukrainian Center for the Diagnosis and Treatment of Breast Disease, located within the Ukrainian Research Institute of Oncology and Radiology in Kyiv ("Kyiv Institute");
- The Chernihiv Oblast Oncology Center (Dispanser) ("Chernihiv Center"), which serves an area heavily exposed to radiation from the Chernobyl accident; and

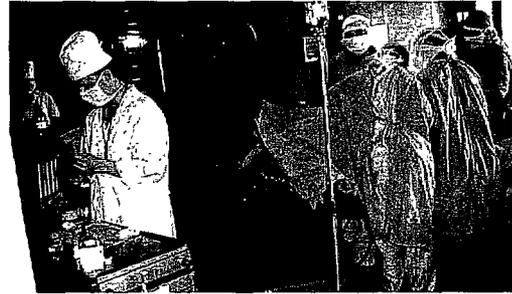


*Chernihiv Oblast Oncology Center*

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- The Odesa Oblast Oncology Center (Dispanser) (“Odesa Center”), serving an oblast with one of the highest incidence rates of breast cancer in Ukraine.

In the course of the project, additional partnerships were formed with the following institutions which all contributed actively to the project success:

- The Kyiv City Oncology Center (“Kyiv City Center”);
- The Ukrainian Association of Radiologists; and
- The Pathology and Oncology Departments of Lviv State Medical University.



*Surgery Department at Kyiv City Oncology Center*



*PATH Consultant, Dr. Anderson, from the University of Washington, Seattle, and his Ukrainian colleagues from the Oncology Department of Lviv State Medical University*

The project team consisted of PATH staff and consultants based both in Seattle and in Kyiv. The original staff continued to serve throughout the entire project, which greatly aided project continuity. The American consultants were affiliated with Washington State-based institutions, including the University of Washington, the Fred Hutchinson Cancer Research Center, Madigan Army Medical Center, Providence Breast Cancer Program at The Polyclinic, Group Health Cooperative of Puget Sound, and the Bellingham Breast Center. As the project advanced, the consultant group expanded to provide the needed technical support. A list of the project team members is given in Attachment A.

## **ASSESSMENT FINDINGS**

A PATH team of eight U.S. specialists undertook an initial two-week assessment visit to the Ukrainian partner institutions at the outset of the project. In addition, a systematic information-gathering exercise and several baseline surveys were completed by PATH Ukraine staff and consultants. Since problems with pathology also became apparent in the initial assessment, a more detailed pathology review was undertaken later in the first year. A limited assessment of radiotherapy was carried out in the third year of the project and is described in more detail in the section on influencing Policies and Practice Guidelines. The combined assessment findings were discussed in a meeting with Ukrainian partners and shaped the priorities of the initial work plan. A full report of the assessment was given to USAID in 1997; a few highlights are given here.

**Screening.** While clinical breast exam (CBE) was officially mandated, technique was poor due to inadequate training, performance was sporadic, and there was no system to track either coverage or results. Mammography screening was practically nonexistent. Information about breast self-exam (BSE) was limited. Public understanding about the value of early detection was low.

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The distribution of Ukrainian patients is weighted more toward advanced stages of disease. Teaching breast self-examination and upgrading clinical breast examination might be successful in moving patient staging from Stages III and IV toward Stage II. However, building public awareness for health promotion would be challenging, owing to the competing preoccupations of the population with pressing economic and other quality of life issues.

**Diagnosis.** A strong need was found for training in many aspects of high-quality diagnostic mammography. Mammography equipment for diagnosis was mostly outdated; film quality was poor, and availability was very limited. Needle biopsy was used on a very limited basis and was of uneven quality, partly because it was done without ultrasound guidance.

Although capable pathologists were identified at all project sites, microscopes were antiquated and inadequate; microscope slides, coverslips, and specimen stains were in short supply; slide preparations were frequently scraped off and the glass slides reused (in one site, specially-cut pieces of window glass were in use as a slide substitute). Supply constraints limited the number of preparations made per patient specimen, affecting proper sampling of pathology specimens. The Ukrainian pathologists were aware of newer diagnostic tests such as hormone receptor determinations, but lacked the test kits and reagents to do the studies themselves. Although medical pathology literature was available in varying degrees at all the sites, the literature is outdated and mostly Soviet in origin. Access to international literature is extremely limited.

**General Approach.** The predominant Ukrainian view of the pathophysiology of breast cancer was found to be similar to an older American view, one that has been displaced in the United States and Europe by a paradigm based on evidence from international clinical trial studies in recent decades. The Ukrainian view of disease progression explained in great measure their different approach to breast cancer treatment and to management of benign breast disease.

**Surgery.** Intraoperative conditions observed were sub-optimal: anesthetic monitoring and airway management were minimal and subjected patients to undue risk; inadequate volume replacement therapy subjected patients to the stress of a hypovolemic state. These findings are especially distressing, given the older ages of typical breast cancer patients already at greater risk for heart disease and stroke. Moreover, antiseptic practice in the operative suite was at a lower level than would have been seen in the United States, partly because of a lack of supplies, but also due to a very different level of concern for antisepsis.

The Ukrainian breast surgeon is typically at the undisputed pinnacle of the medical professional hierarchy in breast cancer management. Other medical specialists are in a subordinate role, there being little evidence of multidisciplinary team functioning as practiced in the United States. For example, at the Kyiv Institute, the surgeons manage their patients' systemic therapy.

**Chemotherapy.** PATH consultant oncologist, Dr. Julie Gralow, noted that Ukrainian oncologists often used lower doses of chemotherapeutic agents than was internationally recommended. Reasons for this practice stemmed from fear of toxic side-effects and the high-cost of the drugs.

**Provider-patient Relations.** Women are typically not told they have cancer, even when they have to undergo mastectomy. Instead, Ukrainian physicians usually inform only other family members about the

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cancer diagnosis. Although some health professionals expressed support for more candor in discussions with patients, the cultural norm and official policy did not support revealing the cancer diagnosis to the patient out of concern that such frankness would dash the patient's hope for survival.

The woman with a breast symptom or lesion must typically rely on the physician's verbal advice for every aspect of care. There were few, if any, supplemental patient educational materials to prepare the woman for upcoming events in the course of diagnosis and treatment, or to offer explanations about her symptoms or concerns.

**Rehabilitation.** Although there is a good system in place for tracking women after treatment, there were few materials or resources available to help her physical or psychological recovery.

## MAJOR PROGRAM COMPONENTS

The program components and strategies, as defined during the early assessment trips, were placed into a three-year time frame. Activities and major accomplishments and constraints related to each of the five major strategies are described below.

### Training for Health Care Providers

A variety of methods were employed to expose health workers to new ideas and techniques. These included providing opportunities both within Ukraine and abroad. Most learning sessions were specially designed for the project, but wherever possible, PATH took advantage of existing resources like international conferences, established curricula, or published literature.

### External Learning Opportunities

**Study Tour to the United States.** In October 1997, PATH organized a two-week study visit for nine physicians from the three project sites, the Ministry of Health (MOH), the USAID Mission, and PATH Ukraine, to breast cancer screening, diagnosis, and treatment facilities in the Seattle area. These individuals participated in a core lecture series covering the principles of breast cancer therapy, screening, psychosocial support for the patient, and a review of international research on Chernobyl radiation effects. Various members of the group were able to observe multidisciplinary case review sessions, breast surgery, and even a survivor support group session. They visited several regional diagnosis and treatment centers (University of Washington Hospital, Group Health Cooperative, St. Joseph's Hospital in Bellingham, Providence Hospital, and the Madigan Army Medical Center), and were exposed to the work of private organizations serving the needs of breast cancer survivors



October 1997 Study Tour Participants at the Race for the Cure, Seattle, Washington

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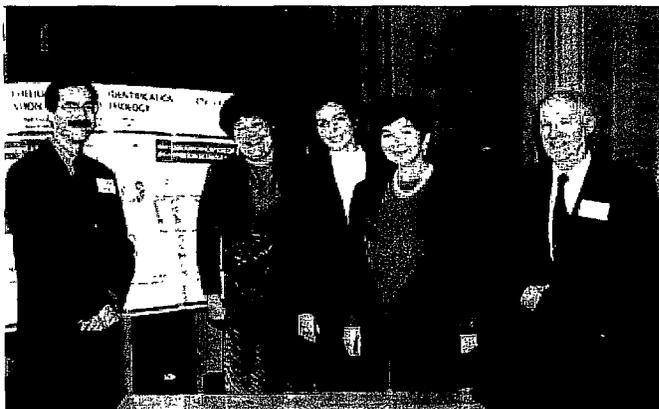
(American Cancer Society, Cancer Lifeline). Ukrainian surgeons in the delegation were able to observe surgical practice at all the participating treatment centers. Ukrainians were able to visit services organized for patient education and public awareness, such as the Cancer Information Service of the Fred Hutchinson Cancer Research Center. In addition, the breast cancer specialists observed public events sponsored by voluntary organizations such as the *Race for the Cure* of the Susan B. Komen Foundation, and an art benefit for the American Cancer Society.

***International Meeting Attendance.*** PATH made possible the participation of certain Ukrainian physicians and scientists in international meetings by subsidizing their expenses.

- Doctoral candidate, Ms. Oksana Akhova, pathology technician at the Kyiv Institute, attended the First European Breast Cancer Conference held in Florence, Italy, September 29-October 3, 1998. Her abstract was accepted as a poster.
- In fall 2000, breast surgeon, Dr. Andriy Nehman, of the Kyiv City Center participated in the Second European Breast Cancer Conference held in Brussels, Belgium.

***Fellowships.*** Five Ukrainian physicians came to Seattle for short-term fellowships at various times during the project.

- Three pathologists studied breast pathology and immunocytochemistry diagnostic techniques with PATH consultant, Dr. Allen Gown at PhenoPath Laboratories. These were Drs. Liubov Zakhartseva of the Kyiv City Center and Alla Moloshok of Chernihiv Center in 1998, and Dr. Marta Servetnyk of the Lviv State Medical University in 1999.
- One mammographer from the Chernihiv Center, Dr. Yuliya Zakharchenko, studied with PATH consultant radiologist, Dr. Connie Lehman, at the University of Washington in July/August 2000 under a fellowship from the International Union Against Cancer (UICC).
- At the initiative of PATH consultants, Drs. Ben Anderson and Julie Gralow of the University of Washington, Dr. Roman Shyian, a surgeon from the Lviv Oblast Oncology Center and the Lviv State Medical University visited the University Hospital in Seattle in April 2000.



*Drs. Gown, Moloshok, Servetnyk, Zakhartseva and Professor Zerbino, Chief of Pathology of the Department of Lviv State Medical University, at the November 1999 Conference*

***Visits to Neighboring Countries.*** PATH sponsored a visit to Poland in 1999 for a delegation of physicians from the MOH and the Chernihiv Center, for professional discussions with Polish colleagues. In September 2000, PATH sponsored a visit to Poland by Dr. Yakov Babiy, head of the Ukrainian Association of Radiologists (UAR), to learn from the Polish experience with mammography screening and quality control.

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## Skills Workshops

**Clinical Breast Examination (CBE).** Upgrading and expanding the skills of healthcare workers in CBE who are most likely to see asymptomatic women was a fundamental strategy for increasing the early detection of breast cancer. To implement this strategy, PATH consultant, Dr. Rick Clarfeld, a breast surgeon, collaborated with PATH staff to develop a Clinical Breast Examination Curriculum consisting of a syllabus, a set of photographic slides, and a videotape. Dr. Clarfeld made two trips to Ukraine to teach CBE to physicians at project sites using this curriculum. These physician trainees became master trainers who, in turn, would train other health care workers in CBE. PATH consultant oncologist-gynecologist, Dr. Galina Maystruk, coordinated further training sessions and assured distribution of the curricular materials.



*Trainees practicing CBE skills with breast models, Kyiv, October 1998*

**Breast Imaging for Radiologists.** Dr. Lehman made three trips to Ukraine to lead seminars and workshops on reading screening mammograms and performing ultrasound-guided biopsies. Dr. Lehman coordinated her teaching presentations with Ms. Louise Miller, PATH consultant mammography technologist, who contributed important information on mammography quality control. In addition, PATH supported part of the printing costs for a Russian translation of the American College of Radiology (ACR) BI-RADS™ reference manual (illustrating a standardized set of categories for classifying mammograms), and facilitated the licensing agreement from ACR that permitted the UAR to distribute an authorized translation.

**Mammography Technique for Technologists.** Ms. Miller developed a three-day curriculum on mammography positioning and quality control for technologists, incorporating several manuals used by the ACR and using innovative teaching methods she has devised. This curriculum was the basis for two Training of Trainers (TOT) courses she conducted in 1998 and a subsequent course in 2000 led by two of her original trainees, with Ms. Miller assisting. The written curriculum and two reference manuals were translated into Russian and distributed to mammography technologist trainees, along with an extensive set of teaching slides and mammography films.

**Pathology.** PATH consultant pathologists, Drs. Gown and Hadi Yaziji, presented on pathology topics at the national symposia and summation conference. Following these events, they conducted workshops at the project sites for pathologists. After the second national symposium, a Russian translation of Dr. Gown's manual on immunocytochemical diagnostic techniques was distributed. In addition, laboratory technologist, Ms. Terry Ayers, and her husband, Mr. Russell Ayers, traveled to Ukraine to lead workshops on laboratory techniques and to assist in the installation of new and donated equipment.

**Psychosocial Support.** Based on the results of the early needs assessment, PATH initiated training with doctors and nurses in psychosocial issues. The concept of psychosocial support for breast cancer patients was very new in Ukraine. PATH developed a training curriculum for medical workers that focused on enhancing communication and counseling skills with patients. The curriculum included a

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review of leading-edge research on how stress affects immune system functioning, which, in turn, may influence breast cancer recovery, quality of life, and the chance of recurrence. The two-day training included role-playing to allow medical workers to develop their interpersonal communication and counseling skills. Training activities included:

- developing and translating into Ukrainian the first training manual in Ukraine on psychosocial issues related to diagnosis and treatment of breast cancer patients;
- pretesting and revising the psychosocial curriculum at the Kyiv Nursing School Number 3 with nursing school professors;
- conducting training workshops in psychosocial issues with doctors and nurses at the Chernihiv Center, professors from the Chernihiv regional nursing school, Kyiv City Center, Kyiv Nursing School Number 3, and with masters level social workers from the Kyiv Mohyla Academy;
- contracting a psychologist from the Institute of Social and Political Psychology to serve as a consultant on psychosocial activities;
- conducting a one-day refresher training course with nurses in Chernihiv; and
- providing the training curriculum and aides to nursing professors to conduct ongoing training.

**Anesthesia.** PATH consultant anesthesiologist, Dr. Hugh Allen, visited project sites and provided training in the use of intraoperative monitoring equipment provided by the project and the use of regional anesthesia.

### **Medical Symposia and the Summation Conference**

PATH organized national symposia on breast cancer for physicians in April of 1998 and 1999. Symposia in which both American and Ukrainian doctors presented papers were used as a way to expose the medical community to new ideas and the evidence supporting them, and to generate discussion. Often, there were already a few Ukrainian proponents of these newer ideas, but the symposia gave them a legitimate platform and support from international experts.

The first symposium, held in Kyiv, focused on the management of the breast mass. PATH consultants, Dr. Cary Kaufman, a breast surgeon, and Dr. Yaziji, a pathologist, led the two-day symposium, attended by more than 30 Ukrainian specialists from seven oblasts. PATH consultants had come to recognize some differences in concepts of pathogenesis and treatment management in Ukraine. To stimulate dialogue, Drs. Kaufman and Yaziji organized a series of six clinical case discussions intended to represent a spectrum of breast disease types. Each case discussion was translated into Russian and illustrated with photomicrographs, reproductions of mammograms, and ultrasound studies. The consultants presented these case studies as a basis for further discussion of disease types and clinical management. All participants received packets with the case studies in addition to a rich bibliography of international medical literature. The Ukrainians also made presentations illustrating their perspective. The ensuing discussion was lively, revealing that the Ukrainian colleagues had had infrequent opportunities to come together to discuss clinical approaches in this manner; they seemed very appreciative of this opportunity. In addition, the discussion revealed substantial variances in approach and philosophy among participants. It was explained that in the days of the Soviet Union, open collegial discussions were relatively infrequent.

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The second national symposium, held in Odesa and co-sponsored with Odesa Medical University, discussed the modern systemic therapy of breast cancer and the role of immunocytochemical pathology techniques as an aid in the diagnosis of breast cancer and in the choice of appropriate systemic therapy. Dr. Gown, a pathologist, Dr. Gralow, a medical oncologist, and Ms. Denise Bowls, an oncological nurse, made presentations. PATH translated their written lectures into Russian and distributed them to all participants. In addition, Ukrainian colleagues were invited to submit abstracts that were published in a bulletin for general distribution at the conference. More than 100 doctors from 13 oblasts attended the meeting, and 36 abstracts were included in the bulletin. A number of Ukrainian collaborators presented, including project partners: Drs. Natalya Martsinkovskaya (Odesa), Natalya Voitko (Kyiv), Vladimir Zotov (Chernihiv), Yaroslav Shparyk, and Borys Bilynsky (both Lviv). Dr. Bilynsky gave an excellent up-to-date review of chemotherapy. Dr. Zotov presented an overview of the Chernihiv screening project. Dr. Martsinkovskaya gave a review of the project chemotherapy protocol. Dr. Shparyk talked on the economic and ethical issues of chemotherapy. Dr. Voitko's talk on the psychosocial adaptation of the breast cancer patient was well received. She discussed topics that PATH had often been admonished were taboo in Ukraine, such as telling the patient of her cancer diagnosis.

The PATH Breast Cancer National Summation Conference was held in November 1999 outside Kyiv. This conference provided an opportunity to present results of the three-year program and to highlight issues in early diagnosis and treatment. PATH consultant specialists (Dr. Anderson, breast surgeon; Dr. Gown, pathologist; and Dr. Gralow, medical oncologist) reviewed topics in their fields and demonstrated interdisciplinary clinical team functioning by collaborating in the presentation of some illustrative breast cancer cases. The role of psychosocial support in patient care was given prominence at the conference, with the participation of women survivors in addition to presenters from Poland and



*Breast Cancer National Summation Conference,  
November 1999, Kyiv*

Russia. A highlight of the program was the panel of eight breast cancer survivors who talked about their experiences as patients and, in some cases, appealed to doctors to treat them with greater openness.

Approximately 100 people attended, about 70 from outside of Kyiv representing 18 oblasts. PATH published the proceedings of this conference in Ukrainian and distributed them to conference participants and interested professionals. This was the first PATH conference in which commercial firms were invited to set up displays, in return for a contribution to the program. Bristol Myers Squibb, Orion, Astra-Zeneca, and the Kodak film distributor, Exim, had booths.

A complete list of training events conducted by PATH over the project period is provided as Attachment B.

### **Medical Literature Dissemination**

In addition to the mammography and pathology manuals described above that were translated in full, PATH distributed abstracts downloaded from the NCI CancerLit Breast Cancer Literature database, at

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<http://cancernet.nci.nih.gov/clinpdq/canlitxt/breast.html>. The Ukrainian physicians had very favorable views of the NCI CancerLit Breast Cancer Literature database of monthly compilations of English abstracts of leading scientific articles in chemotherapy, radiotherapy, surgery, and screening and prevention of breast cancer. However, the project sites could not easily access the World Wide Web to download and print these articles. The Ukrainian collaborators requested hard copies of the materials, since printing and paper supply are problematic. Moreover, access to computers was not universal, so just reading the text from a computer screen was not a practical option for most health professionals. Therefore, PATH distributed hard copies of the abstracts to the project sites. Over time, medical specialists from other oncology centers or medical training institutions also requested these abstracts, thereby widening the impact of the distribution. The issue of medical literature access in education is discussed further later in this report.

Major project accomplishments related to exchanging professional knowledge and skills include:

- Strengthening CBE capacity. CBE master trainers continue to train actively on their own. More than 1,500 health care workers have been trained so far. Training units have been set up at the Chernihiv and Odesa centers. The CBE curriculum developed by PATH has been adopted in Ukrainian nursing schools nationwide, and components of it have been incorporated into a new nursing textbook written by Dr. Tetiana Khokhlich, Professor at Kyiv Nursing School Number 3.
- Improving mammography technique and interpretation. Ukrainian mammography technologist trainers have conducted their first round of training using the PATH curriculum. The translated ACR BI-RADS manual will provide a basis for standardizing mammography interpretation. The UAR has agreed to establish a certificate course in mammography for technologists and certification standards for mammography interpretation.
- Promoting psychosocial support for the patient. Several hospitals have established close relations with survivor groups. PATH consultant, Dr. Khokhlich, has continued to use the psychosocial curriculum to train doctors and nurses in schools of medicine and nursing throughout Ukraine. The curriculum has been approved and integrated into the standard curriculum of the nursing school.
- Clinical practices are beginning to change in project sites and elsewhere. New approaches to pathology, such as immunocytochemical techniques and improved biopsy surveillance and quality, have been introduced. As a result of observation of surgery in Seattle, exposure to medical literature, and symposium presentations, breast conserving surgical approaches are being implemented or considered at the project sites. PATH consultants have demonstrated the team approach to the clinical management of the breast cancer patient in visits to the

**Changes in Provider Practices  
and Attitudes with Regard to  
Early Detection**

(as seen during project baseline  
and follow-up surveys)

- Gynecologists are more likely to do CBE in routine visits (66% →82%).
- More medical staff report having had CBE training (52% →79%).
- More providers recommend BSE monthly (66% →92%).
- More providers believe survivors would be a good source for screening messages (27% →48%).

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project sites and in lectures at the symposia and the summation conference. Ukrainian specialists in surgery, oncology, radiology, and pathology at the project sites have begun to acknowledge the value of collaboration in a team approach to the patient.

Major project constraints related to exchanging professional knowledge and skills include:

- Institutionalizing the various training modules, such as CBE and immunocytochemistry (ICC) methods, into preservice and postgraduate medical curricula will take time. Even when they are officially incorporated into these curricula, it will take many years before all providers are exposed to these new ideas. Funds for special training courses are very limited.
- Limited access to international literature and conferences will be a continuing constraint on the ability of providers to keep up with scientific developments in a field that is moving rapidly.

### **Changes in Provider Practices and Attitudes with Regard to Psychosocial Aspects**

(as seen during project baseline and follow-up surveys)

- More providers encourage patients to talk openly (38% → 72%).
- More providers are likely to encourage patients to talk to survivors (2% → 49%).
- More providers are likely to encourage patients to talk to family members (18% → 35%).
- More providers believe survivors should be trained to give support (0% → 62%).

### **Provision of Equipment and Supplies**

An important aspect of the project was to provide equipment and supplies in order for the various project components to carry out their functions. Mammography machines were established at project sites, pathology practices were upgraded, and audio-visual aids were made available for ongoing training. PATH secured a limited amount of intraoperative monitoring equipment through the U.S. Department of Defense (DOD), which was distributed among the project sites. PATH consultant technologist, Ms. Ayers, instructed lab staff in the proper maintenance of the supplementary pathology equipment and prepared a syllabus on procurement sources to assist the Ukrainians in supplying their ongoing needs for laboratory materials. Much of the equipment and supplies were delivered to Ukraine through the assistance of the U.S. State Department, New Independent States Humanitarian Division.

The following key pieces of equipment were supplied (see complete list of equipment and essential supplies purchased and donated by the project in Attachment C):

- four mammography units and film processors
- mammography film, chemicals, accessories
- one ultrasound machine
- pathology equipment (e.g., microscopes), reagents and supplies, hormone receptor test kits
- surgical equipment and supplies
- seven computers, two slide projectors, three fax machines, two VCR/TVs
- thirty courses of chemotherapy

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Major project accomplishments related to equipment and supplies include:

- A broad array of items were provided despite a very limited budget, primarily through use of donations and special discounts.
- More than 21,000 women received high-quality mammograms using equipment and supplies provided by the project.

Major project constraints related to equipment and supplies include:

- Manufacturer support of specialized equipment like mammography units was weak during the project, although it appeared that it was being strengthened near the end of the project.
- Financial constraints in the health care system will continue to make it difficult to get adequate supplies of film, chemicals, reagents, and other consumables and to pay for equipment servicing when it is needed.

## **Patient Understanding and Public Awareness**

Although the information needs of breast cancer patients and the general public have specific and differing requirements, they are affected by many of the same general perceptions of the disease and of the experience of patients and survivors. From the first quarter through the completion of the project, PATH developed and disseminated informational materials and facilitated public awareness campaigns to increase Ukrainians' understanding of breast cancer. While efforts to increase patient understanding were initially focused on informational print materials, the focus broadened later to encompass innovative and surprisingly successful survivor support and outreach programs.

To initiate these efforts, PATH first contracted with Ukrainian Surveys and Market Research (USM) to conduct knowledge and attitudes surveys with medical providers regarding their attitudes toward providing patients with information about their disease. To determine women's attitudes toward the disease, USM conducted focus group discussions (FGDs) with women who had experienced breast cancer and those who had not. In addition, PATH conducted small baseline surveys of provider attitudes and practices related to the care of breast cancer patients and to early detection activities in the project areas; these surveys provided insights useful in designing the project strategies.

The major findings that influenced PATH's information, education, and communication (IEC) focus included:

- most physicians did not tell their patients that they had cancer and did not feel it was their responsibility to inform their patients about the disease;
- most physicians did not feel qualified to deal with emotional reactions of their patients;
- the majority of women with breast cancer were very dissatisfied with treatment, feeling that they received false hope and inaccurate information from their physicians;
- most women wanted more information about their condition so that they could plan the future with their families; and

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- the majority of women wanted information on the disease so they would: (1) have a better understanding of how it would affect their lives; (2) understand the treatment regimens and their choices regarding treatment; and (3) learn how they might help themselves in combating the disease through exercise and better nutrition.

### **Patient Education**

In response to these initial research findings, PATH developed a total of 17 print materials to inform women about the disease—these materials were the first printed information most of them had ever seen on breast cancer. (See Attachment D for a full list of materials developed by the project.) PATH ensured that all materials were thoroughly reviewed and approved by Ukrainian physicians as well as pretested with breast cancer patients in the three project sites.

At the request of a group of Ukrainian breast cancer survivors, the brochure on recovery was adapted and reprinted from one that was developed by the health department in Minsk, Belarus.

All IEC materials were printed in Ukraine (over 350,000 total pieces) and distributed to colleagues at the MOH (Dr. Tamara Irkina); the three primary project sites; Kyiv City Center; the Health Education Centers serving the three sites; and the oncology centers in Zaporizhia, Zhytomyr, and Cherkasy; PATH-sponsored training seminars and conferences; and through NGOs serving breast cancer survivors.

Throughout the project, PATH collaborated with American International Hospital Alliance (AIHA) to strengthen breast cancer services. Related to IEC activities, PATH authorized AIHA to translate into Russian and reprint seven PATH brochures, four informational flyers, and one poster for use in their projects in Russia and Russian-speaking areas of Ukraine. AIHA distributed the materials through their Women's Wellness Center at the Left Bank Hospital. They gave PATH permission to revise and reprint one of their brochures in Russian, *What You Need to Know About Breast Cancer*.

All the materials were extremely well received, as demonstrated by the tremendous demand and need to reprint several materials. To facilitate easy reproduction of the print materials, PATH has posted them on its web page at URL address: [http://www.path.org/resources/ukra\\_breast\\_ca\\_material.htm](http://www.path.org/resources/ukra_breast_ca_material.htm)

### **Public Awareness Campaigns**

The primary purpose of the public awareness media campaign was to support the pilot screening project in Chernihiv raion, with ancillary efforts focused on other areas of Ukraine. To prepare for the Chernihiv campaign, PATH conducted the following activities:

- Distributed print materials throughout Chernihiv raion (which is adjacent to the Chornobyl nuclear reactor).
- Produced three 30-second TV spots containing key messages regarding the importance of early detection through breast self-exam, clinical breast exam, and mammography. The TV spots were produced in collaboration with producers from TV station 1+1 and were carefully pretested. The spots were broadcast through the efforts of Dr. Zotov working collaboratively with the Chernihiv Oblast Health Education Center and the Center for Media Initiatives in Kyiv.

- Produced three 30-second radio spots based on the TV spots, with scheduled broadcasts during the campaign.
- Collaborated with Dr. Zotov and a committee of local women to conduct outreach within the community—the most successful event was on national Women’s Day.
- In collaboration with USAID’s press office, developed a press packet that was distributed to journalists covering the launch of the Chernihiv screening project and conducted an informal seminar with media journalists.

The Odesa Center conducted its own public awareness campaign with assistance from the Odesa Oblast Health Education Center. They broadcast the PATH TV and radio spots and distributed the print materials as part of an effort to increase awareness of their screening and clinical services. In Kyiv,

**Changes in Public Awareness  
and Attitudes about  
Early Detection**  
(as seen during baseline  
and follow-up surveys)

- 96% of those without prior CBE were willing to have CBE after project (vs. 81% before); among women 60+ years, 97% were willing (vs. 48%).
- Level of information was high before (88% had seen something) and did not change.
- Awareness of public information among medical staff increased 56% →89%.

print materials were distributed through the Kyiv Institute, the MOH (Dr. Irkina), numerous training courses, Dr. Maystruk’s NGO (Foundation for Women’s Health and Family Planning), the Kyiv City Health Education Center, and the Kyiv City Center.

PATH efforts resulted in several newspaper and magazine articles being published about the project, including articles in Chernihiv newspapers and the national newspapers, *The Weekly Mirror* and *Argument and Facts*.

To encourage ongoing public awareness campaigns and provision of information on breast cancer, PATH developed an IEC strategy for providing breast cancer throughout the country. This strategy includes mass media campaigns, development of print materials, psychosocial training, and other related activities, and is intended as a guide for the MOH and NGOs that are committed to continuing IEC interventions related to breast cancer.

### **Increasing Psychosocial Support for Patients**

PATH conducted a range of activities that unexpectedly led to accomplishments and ongoing activities beyond the project’s original mandate.

**Going Beyond Patient Information.** A key objective of the project has been to improve the quality of life of women experiencing breast cancer. In addition to providing educational materials and training medical providers in psychosocial care, the project sought to achieve this objective by:

- identifying breast cancer patients and medical providers already active or interested in coming together with others for the purpose of mutual support;
- identifying role models and opportunities to meet other survivors from throughout Ukraine as well as from neighboring countries and the United States;

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- fostering the development of hospital- and community-based support groups;
  - providing training in peer counseling, and developing a Peer Support Volunteer program model;
  - forging alliances with medical providers; and
  - supporting training in organizational development and fundraising.

The actual scope of work and degree of success in this area, however, have extended far beyond our original expectations, and the establishment of a survivor “movement” in Ukraine promises to be one of the most sustainable outcomes of the project.

***Identifying Survivors and Medical Providers.*** Our initial approach was to work through our partners to identify women known to medical providers who had expressed interest in developing mechanisms for providing mutual support among breast cancer patients. In March 1999, Dr. Zotov, Chief Doctor of the Chernihiv Center, introduced PATH staff to two such women. Both had recently completed treatment for breast cancer, and both were active in maintaining phone contact with women with whom they shared the hospital ward post-surgery. In addition, both aspired to establish a “club” that would provide emotional support to hospitalized patients, to arrange for outings and social activities for survivors, and to prepare articles and other materials to promote public awareness about the disease. Dr. Zotov was fully supportive of their plans and offered to facilitate as much as possible. During the same technical visit, PATH staff also met with women in Kyiv with similar interests. These early discussions provided the basis for the survivor group strategy that emerged.

***Providing Role Models: Seminars with U.S. Survivors.*** Essential to the empowerment of women with breast cancer with whom we were working—and eventually to the formation of survivor groups—was the use of role models. In May 1999, PATH hired two American breast cancer survivors, representing a self-help organization called SHARE, based in New York City, as consultants, to convene a series of seminars in Chernihiv and Kyiv with breast cancer patients and survivors, as well as with medical personnel. The purpose of these meetings was to provide assistance to the women in determining which activities they would like to pursue (i.e., hospital-based peer group and/or individual psychosocial support, community-based peer support, advocacy, public awareness, etc.) and to identify appropriate ways in which PATH could assist them. The consultants (Ms. Bella August and Ms. Odette Peterson from SHARE, New York) structured the seminars so that the first part of each was devoted entirely to women sharing their stories. The consultants initiated this discussion, sharing their own stories to model, in effect, how support groups work. They intentionally used the word “cancer” openly and freely in describing their own past illnesses. This seemed to have an effect, as many of the women who subsequently spoke also used the word *rak* (cancer) when talking about their experiences. The second part of the seminar was devoted to practical discussions regarding priority setting.

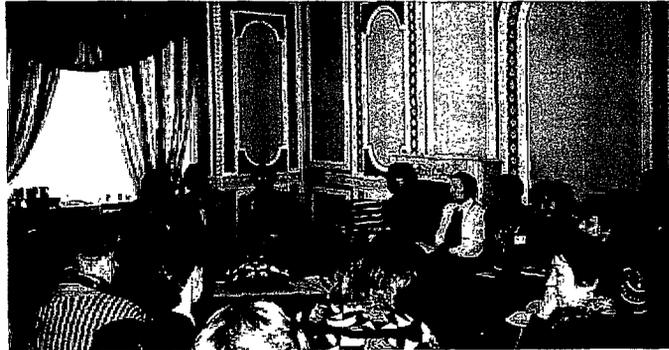
These seminars proved instrumental in both inspiring survivors to organize themselves and clarifying the principal goals and objectives of their groups. In addition, specific requests for technical assistance emerged. First, women in both sites requested training in psychological support for breast cancer patients so that they would feel more qualified to go into the hospitals and meet with patients. Second, both groups expressed a great need for additional information on breast cancer and asked for our assistance in organizing educational seminars for women as well as in continuing to source articles, videotapes, and other resources for them. Third, when asked, women said that they would be willing to

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participate in the National Summation Conference in November 1999 as a way of promoting awareness. Finally, all women expressed a strong desire to meet women from other countries involved in similar work.

***Providing Role Models: Regional Exchanges.*** Over the course of 1999-2000, numerous exchanges were organized between Ukrainian survivors (and medical providers) and their counterparts in Poland and Russia. The importance of these exchanges cannot be overstated. These opportunities to meet breast cancer survivors and professionals who are working towards similar goals in countries with similar political and economic backdrops has been essential in catalyzing Ukrainian women to action, as they witnessed firsthand the range of possibilities that could be applied to their own efforts. The various exchanges are listed in Attachment E.

Another group of survivors returned to Poland in October 2000, with separate funding. Finally, Ukrainian survivors have been invited to participate in a regional conference for breast cancer survivors that will be convened in Warsaw in September 2001.



*Meeting of the Breast Cancer Survivors from Kyiv and SHARE representatives from New York, May 1999*

***Outreach.*** Because the concept was new to Ukraine, the project undertook to model how a volunteer outreach program led by survivors could function. This effort is described below in the section on “Policy and Practice Guidelines.”

Major project accomplishments related to patient information, well being, and public awareness include:

- Both print and audio-visual materials were distributed to interested parties in all oblasts in Ukraine and to the MOH.
- A willingness to seek CBE and mammography screening increased, especially among older and more rural women who could benefit most.
- Patients (and providers) are spreading the word about self-care after treatment and are taking advantage of new information about how to reduce the debilitating effects of mastectomy and chemotherapy.
- Either hospital-based or community-based survivor groups are active in eight oblasts: Chernihiv, Kyiv, Lviv, Zhytomyr, Kherson, Kharkiv, Zaporizhia, and Mykolayiv, with inquiries from survivors and oncology centers in Luhansk, Dnipropetrovsk, and Donetsk also coming in regarding how to start such groups. These groups are linked to each other and to groups in Poland, Russia, and the United States.

Major project constraints related to patient information, well being, and public awareness include:

- The MOH has limited resources for reprinting and distributing the materials on a wider basis.

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- In the face of reorganization of the health structure, the responsibility and capacity for coordinated health education services are not clear. Therefore, it was difficult to institutionalize these activities into a central government structure. The efforts will depend on continued local initiative, interest, and resources.
  - Public- or private-funding sources for survivor groups are very scarce. It will be a challenge in these difficult days for the groups to raise even the modest funds they need to function effectively, despite the strong base of volunteerism.

## **Strengthening the Health Infrastructure**

### **National Cancer Registry**

The data produced by the National Cancer Registry are critical to an understanding of both the epidemiology of the disease and the quality and coverage of related health services. Oblast oncology hospitals are responsible for submitting both summary paper records (to the MOH) and database files to the National Cancer Registry. The Registry was in the midst of a multi-year plan to upgrade its systems and the quality of its data when the project started. At the start of our project, Chernihiv was already contributing to the database, but Odesa was not. As a result, stage- and age-specific incidence rates were not available for Odesa. There were also real concerns about the quality of the stage data being submitted by all oblasts; this information was important to evaluating whether screening would contribute to an increase in earlier stage detection.

In order to aid the Registry in its efforts to upgrade, PATH provided a computer and fax-modem, limited technical assistance, and subcontracts to support travel and assistance by central Registry staff to oblast registry staff. Technical assistance consisted primarily of suggestions from the PATH epidemiologist on ways to analyze the breast cancer data in the registry to assess problems in the project partner oblasts and to measure change over time. These data were presented by Registry staff at two conferences sponsored by the project.

The three subcontracts were directed at two activities in Odesa and one in Chernihiv. The first activity, undertaken early in the project, was designed to help Odesa set up and comply with the database. This resulted in full participation of Odesa in the database program. The second activity in Odesa was designed to address a suspected problem of duplication of cancer cases; again, national registry staff worked with oblast registry staff to install software to check for duplicates and went through several years of data with them. They also emphasized the importance of entering complete morphology, tumor/node/metastasis (TNM) data, and full date (rather than just year) of birth. In Chernihiv, a sample of breast cancer case charts were pulled and compared with the registry information for accuracy and completeness, under the supervision of national Registry staff. Missing data were added, and refresher training on how and why to enter key categories of data was given to oblast registry staff. As a result of these three activities, a substantial improvement in the quality and completeness of oblast registry data (using key variables routinely measured by the national registry staff) was observed (see Table 1 below).

**Table 1. Improvements in Cancer Registry Data**

	Breast Cancer Cases	Morphology noted (%)	Location noted (%)	ICD-4 code noted (%)	TNM noted (%)	Full name (%)	Full date of birth (%)
Chernihiv							
1998 (OLD)	312	57.4	42.6	34.4	22.8	100.0	0
1998 (NEW)	333	95.2	100.0	92.5	70.3	100.0	6.9
Odesa							
1997 (OLD)	1109	62.8	65.8	63.0	59.7	69.0	51.3
1997 (NEW)	1138	99.6	99.7	99.6	89.9	77.4	64.2
1998 (OLD)	1100	96.8	99.9	96.6	99.0	99.9	95.9
1998 (NEW)	1053	100.0	100.0	100.0	99.5	99.9	95.9

In Chernihiv, most essential measures of completeness went up considerably (from 23%-57% initially to 70%-100%). The data for Odesa show that there was a marked improvement between 1997 (old) and 1998 (old) data (from 51%-66% to 96%-100%), as a result of the first activity there, and a further improvement (through the removal of nearly 50 duplicate case records) in the 1998 data as a result of the second round of assistance.

### Local Screening Data

As part of the pilot early detection program in Chernihiv, the local health information system was modified on a test basis to collect data on the outcome of clinical breast exams (discussed below). When it became clear that this modification made it possible for Chernihiv raion to calculate screening coverage (by age group and geographic subdistrict), to estimate rates of breast abnormalities, to monitor quality of CBE, and to follow individual women for referral, project staff began investigating ways to make the modification part of the national system. The modification was discussed in the final Early Detection meeting, but there was not sufficient time at the end of the project to negotiate final adoption of this information system change.

Major project accomplishments related to health infrastructure strengthening include:

- Odesa cancer registry statistics were greatly improved in accuracy, completeness, and credibility.
- The National Cancer Registry (NCR) increased their analysis and use of breast cancer statistics to address policy and program planning issues.

Major project constraints related to health infrastructure strengthening include:

- The shortage of trained staff and appropriate computers at the NCR make it difficult for them to process information in a timely way or to strengthen the quality of the data collected. For example, official 1999 data will not be available until mid-2001.
- The existence of parallel data from the NCR database and the routine MOH non-database health information system produces conflicting and confusing data.

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## Influencing Policies and Practice Guidelines

An important intention of the project was to help influence national and local policies and practice guidelines related to breast cancer in several areas, through discussion, pilot demonstration, and provision of written information. The needs related to early detection, chemotherapy, and ICC methods were identified in the initial assessment phase; opportunities to address the remaining issues were identified as the project proceeded. Progress was achieved to varying degrees in the following selected policy or practice areas:

- demonstration of an early detection strategy in a pilot area;
- demonstration of proper chemotherapy dosing through a clinical trial;
- demonstration of the value of ICC methods for better diagnosis;
- demonstration of the feasibility of survivor outreach and advocacy initiatives;
- assessment of radiotherapy capacity and recommendations for improvement; and
- modification of surgical approaches to breast cancer and benign breast disease.

### Early Detection Strategy

A major priority of the project was to assist Ukraine in increasing the proportion of breast cancer cases detected at an early, more treatable stage using the available resources of the country. To this end, PATH established a pilot screening program in Chernihiv oblast using both mammography and CBE for screening and strengthening diagnostic services (through training and improved equipment). The purpose of the pilot program was to try out different screening strategies so that local and national health officials could study the advantages and disadvantages of each and gain experience in organizing a comprehensive screening and diagnosis program. A substantial public awareness campaign using television, radio, posters, brochures, and newspaper and magazine articles was launched in 1998.

**Mammography Screening.** Since there was only one radiologist available at the Chernihiv Center for the first two years of the project, and the project had resources to purchase only a few mammography units, we decided to place just one modern mammography unit (in addition to the diagnostic one they already had) in the oblast for screening. A fully utilized mammography unit can screen about 6,000 women each year, so the program was targeted at women ages 45-69 in the nearby Chernihiv raion and Chernihiv city. The age range was selected based on the fact that the rate of breast cancer among women younger than 45 was very much lower than among those 45 and above. Women older than 69 were permitted but not actively encouraged to attend for mammography screening, because their numbers were relatively small and they were



*Ms. Kauchma (center front), the First Lady of Ukraine, and Ms. Pifer (right front), the U.S. Ambassador's wife, at the opening ceremony of Mammography Screening Program, June 1998, Chernihiv*

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not expected to have a greatly extended life expectancy if any cancers detected were found at an earlier stage.

The radiologist attended two seminars in Kyiv organized by PATH on the interpretation of screening mammography, and received several technical assistance visits from the project's consultant radiologist from the University of Washington. Radiology technologists from Chernihiv attended a three-day training on proper patient positioning for mammography and quality control for mammography and received several technical assistance visits from the project's consultant technologist master training from the United States. In addition, the radiology unit received assistance in setting up a computerized database to enable them to track all patients screened by mammography. The junior radiologist who joined the unit in the third year of the project showed considerable initiative in working on the database, and used the data to report quality control measures and to generate information on the number of patients served and the results of their mammograms. As of June 30, 2000, (the last date for which data are available) Chernihiv had screened over 4,800 women with mammography over a 24-month period and had identified 89 cancers, of which 61% were Stage I or Stage 0.



*Mammography machine purchased by the project, at the Chernihiv Center*

Although they experienced considerable success in detecting early cancers during the mammography screening program, Chernihiv health personnel also identified several challenges in running a mammography screening program. They had service problems with General Electric (GE), the manufacturer of the mammography unit provided by the project, that were not fully and finally resolved until six months before the end of the project. Until the problems were fixed, the machine was periodically either not functioning optimally or completely out of use. GE acknowledged that their local service program was inadequate and finally contracted with a qualified local firm to take over the responsibility. Despite this improvement and the resolution of the particular problem of the machine, it is clear that routine maintenance and occasional service will remain a challenge since it will require finding the funds for service calls and incurring delays while an engineer comes from Kyiv. Even with the machine running smoothly, the program would not begin to be able to serve all the eligible women in the oblast with the one machine, nor do they anticipate the likelihood of receiving additional mammography equipment in the near future. Finally, as the hospital budget continues to shrink, it is not clear where they will find the funds to purchase the films and chemicals needed for screening mammography on a scale large enough to serve the entire oblast.

***CBE Screening.*** The CBE screening component was designed to serve the entire oblast, but with particularly intense activity in Chernihiv raion. Annual screening by CBE of all women 30 years and older was recommended. Using master trainers who went through a two-day TOT course led by one of PATH's consultant breast surgeons, all gynecologists, feldshers, and midwives in Chernihiv raion and all raion oncologists and raion gynecologists in the rest of the oblast received a one-day training course in proper CBE. In addition, the CBE training module was incorporated into the post-graduate curriculum in Chernihiv, so those who were scheduled for routine post-graduate refresher training during 1999 and 2000 received the CBE training.

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In order to track the results of the intensified efforts, the automated health information system functioning in Chernihiv raion was modified slightly on a test basis. One new variable was added on the outpatient visit form; the health worker had to note only whether CBE was normal, abnormal, or not done. Using this information and the usual patient data, it was possible to generate reports showing coverage by facility and by age group, the rate of abnormal exams by facility or by age group, and the list of names and locations of women with abnormal exams needing further diagnostic evaluation. With the list of names, the raion oncology nurse could follow up with the oncology hospital to find out whether referred women ever attended for further evaluation and to get the results of the diagnosis. Data from this system show that in 1999, nearly 19,000 women aged 30 years and older (89% of those eligible in the raion) had a CBE performed and recorded. In the first half of 2000, 48.2% had already been screened; if that rate continued during the remainder of the year, more than 96% of eligible women would be screened in 2000. Overall, just under 1% of women had an abnormal exam in 1999, with women 45 to 49 having the highest rate of abnormal exams (1.8%).

**Early Detection Workshop and Policy Paper.** Taking into consideration the experience in Chernihiv, the rate and age distribution of breast cancer as reported by the National Cancer Registry, and the available and foreseeable resources in the country, PATH prepared a draft position paper recommending CBE as the primary screening method for the country (see Attachment F). In addition, PATH organized a three-day workshop in September 2000 to bring together about 35 people (from 11 oblasts) with interest and experience in breast cancer early detection activities to discuss their experience, to consider the draft position paper, and to develop recommendations for the country. The agenda and results of this workshop are given in Attachment G.

The final recommendations from the Early Detection workshop:

- supported the proposed strategy of relying on CBE as the primary screening mode while strengthening diagnostic services like mammography, ultrasound, and pathology;
- stressed the importance of expanding the CBE training throughout the country;
- suggested an updated inventory be made of functional mammography equipment;
- addressed several issues of public awareness, data systems, and other training needs; and
- called for the establishment of a Working Group of interested parties to develop these recommendations into a formal document for the MOH to consider.

The report of the meeting was translated into Russian and distributed, along with the position paper, to those who attended and to other key people who had been unable to attend the workshop.

**One-view Mammography for Screening.** There is some debate as to whether a single medio-lateral-oblique (MLO) x-ray view of each breast is sufficient for screening purposes and whether the additional sensitivity derived from a second craniocaudal view is worth the cost of additional film. In the United States and several European countries, where film is a relatively small proportion of the mammography cost and breast cancer rates are quite high, two views are used, while some European countries use a single view under certain circumstances. Because the resource implications for Ukraine are substantial, PATH prepared a position paper (Attachment H) describing the expected tradeoffs in terms of reduced sensitivity (more true cases missed) and increased costs.

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The final recommendations were:

- Do double reading of one-view MLO screening mammography (where possible) before adding a second view.
- Do everything possible to maximize the quality of one-view screening mammography, including training for radiologists and technologists, use of good film and processing chemicals, and maintenance of equipment in good working order.
- When more resources become available, consider using two views for the first (prevalent) screening and one view for subsequent (incident) screens, making sure that prior films are consulted for comparison.

This position paper was translated into Russian and was distributed in September 2000 to Ukrainian radiologists interested in mammography.

### **Chemotherapy Approaches**

In light of the problem of under-dosing identified during the assessment, and a primary project goal of identifying effective, practical, cost-effective, and reproducible breast cancer therapies that can safely be delivered in Ukraine, PATH determined that education about the use of scientific data and experience with clinical trials were important activities. Accordingly, Dr. Gralow collaborated with Dr. Martsinkovskaya at the Odesa Center in conducting a chemotherapy trial. The study was designed to determine the feasibility of delivering a standard-dose “Western” chemotherapy regimen used in the setting of the customary Ukrainian supportive medications and techniques. PATH chose the combination of doxorubicin (Adriamycin) 60 mg/m<sup>2</sup> and cyclophosphamide (Cytosan) 600 mg/m<sup>2</sup> (AC) intravenously every three weeks for four cycles in the neoadjuvant (presurgical) setting. The primary objective was to assess the safety and toxicity of administering four cycles of AC chemotherapy in non-metastatic breast cancer patients. The use of neoadjuvant (as opposed to adjuvant, or post-surgery) AC chemotherapy allowed us to have an early measure of response and effectiveness in the form of reduced tumor size upon completion of the treatment protocol.

All treatments were conducted under the direction of Dr. Martsinkovskaya at the Odesa Center, where thirty patients were enrolled. Toxicity was minimal, with two documented cases of neutropenia (lowered white blood cell count). No treatment-related deaths or non-hematologic grade three or four toxicities were reported. Clinical responses were documented in several patients. We gained valuable insight into the challenges of conducting clinical trials in Ukraine as a result of this study. The issue of informed consent provided a challenge since it is not uniform practice to inform patients of their cancer diagnosis nor to detail the risks as well as the benefits of cancer treatment. The procurement and importation of chemotherapy drugs was an obstacle due to underdeveloped drug distribution systems of pharmaceutical companies and requirements of the Ukrainian customs office which delayed release of chemotherapy drugs by approximately six weeks. An unexpected development was the refusal of subsequent surgery by six women with significant clinical responses who witnessed the shrinkage of their tumor during chemotherapy. These patients felt surgery was no longer necessary because they could no longer palpate their tumor. Drs. Gralow and Martsinkovskaya presented the results of this study at the National Summation Conference where it evoked discussion. We hope that this chemotherapy trial will have an impact on medical oncology practices at the national level in Ukraine. For the Odesa project

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site, carrying out an international oncology protocol gave the staff the expertise to attract contract work with pharmaceutical companies to do other research studies, thus gaining access to new therapies for their patients.

### **New Approaches to Diagnostic Pathology**

The application of immunocytochemistry (ICC) techniques to breast cancer care enhances the precision of the diagnosis and contributes to the rational selection of cancer drugs. While some Ukrainian pathologists were aware of newer diagnostic tests based on ICC, they had had little opportunity to evaluate or work with them due to the lack of access to test kits and reagents. ICC is a field that has rapidly improved diagnosis of tumor types in the field of oncology. These immunochemical techniques are performed directly on biopsy tissue slices mounted on microscopy slides. The immunochemical reactions seek out known target cellular antigens, such as specific cell surface receptors or gene products (proteins) indicative of abnormal cellular DNA regulation. The immunochemical test system consists of specific test antibodies that bind chemically to the cellular antigens of interest and produce a color marker in the process. When the test is positive, the color marker is detectable under the microscope as a stain on the cells. ICC makes it possible to distinguish cancer cells from normal cells, or identify cancer cell biological characteristics that have implications for patient prognosis or treatment choices.

An example of the use of ICC in breast cancer is the hormone receptor test. The presence of cell surface receptors for estrogen and progesterone in breast tissue is normal. When hormone receptors are preserved in breast cancer tissue, the tumor carries a better prognosis and, moreover, is likely to respond to an estrogen antagonist drug such as Tamoxifen. Another example is the HER-2/neu test. Positive ICC staining of breast tissue for the HER-2/neu gene product implies a more malignant biological process, but also suggests that the tumor will be responsive to an anthracycline chemotherapeutic agent, such as Adriamycin (doxorubicin).

Well-applied ICC technique can minimize the use of potentially inappropriate chemotherapeutic agents in a given patient. In a resource-poor country such as contemporary Ukraine, ICC can contribute to a reduction in expensive misapplied therapies. The project provided training, ICC test kits, and other supplies to enable them to gain experience with the new techniques. Although ongoing resource constraints prevent wholesale adoption of these new methods at present, the consensus recommendations of the Early Detection meeting (Attachment G) include a recommendation that hormonal receptor tests at least should become a routine part of the diagnostic evaluation as soon as it is financially feasible.

### **Survivor Outreach and Advocacy Initiatives**

The idea of survivor support groups was relatively new in Ukraine when the project began and challenged many assumptions and policies that were in place. When a greater openness to trying out the concept became apparent in the second year of the project, PATH realized it would be important to demonstrate the feasibility and acceptability of this “Western” concept in the Ukrainian setting.

***Bringing Women Together for Mutual Support.*** For many women with breast cancer, support groups can provide invaluable assistance in normalizing their experience and assuring them that their emotions and reactions are typical and can be managed. A key goal, therefore, was to nurture existing

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efforts and create new opportunities for women to come together for the purposes of mutual support. In some cases (for example, Chernihiv), groups were formed with the active support of the oblast oncology hospital. In other settings (i.e., Kyiv), the groups are community-based, with increasing collaboration with both the Kyiv Institute and the Kyiv City Center being pursued. All groups generally meet biweekly, and no woman is turned away. Although a self-help model formed the basis of both existing and emerging groups, several professional psychologists continue to be invaluable in providing guidance and facilitation. This has not precluded the emergence of leadership among the survivors themselves, however. These leaders, over time, have begun to play essential roles in prioritizing and expanding the scope of activities that the groups undertake. This has effectively pushed the groups beyond their primary function of providing mutual support and into the realm of outreach, advocacy, and activism.

The very formation of survivor groups represents an important challenge to the prevailing practice of keeping the disease shrouded in secrecy—whether at the societal or at the individual level. By coming together to provide mutual support, survivors not only are able to improve their emotional and psychological well-being, which, in turn, may aid their overall recovery, but they gain confidence and courage to speak openly about their feelings, their fears, and their wishes. This often leads to a greater willingness to acknowledge beyond their immediate families that they have had the disease. As women in Ukraine become more willing to publicly acknowledge their fight with the disease, they, too, can play increasingly important roles in public education. Indeed, this process has already begun, as women in several cities have been featured in national and oblast news articles in which they have openly described their stories.

***Development of the Peer Support Volunteer Model.*** As the groups matured and individual members grew stronger both emotionally and physically, many women felt ready to reach out to newly diagnosed women or others who were isolated or otherwise in need of support. Indeed, a number of women already had had experience visiting the hospital wards informally to meet with patients and to offer them emotional support, recognizing that despite the best intentions of medical providers, they simply did not have the time to take on this role. Similarly, given current economic circumstances, it is not feasible for hospitals to hire social workers, psychologists, or health educators to take on this role.

Despite these individual efforts, however, a more structured program with formal collaborations with oncology hospitals had not yet been created, and many women expressed the need for specific training in communication and counseling to better prepare them for this work. As a result, in collaboration with PATH staff and local psychologists, a Peer Support Volunteer Program was established, whereby survivors visit oncology wards to provide information and emotional support to newly diagnosed women undergoing treatment; and a comprehensive training curriculum, tailored to the Ukrainian context, was developed. To date, the training has been conducted by Ukrainian psychologists from the National Institute of Psychology in Kyiv to ensure that survivors are adequately prepared, with the first one occurring in September 1999 in Kyiv. Volunteer programs are now active in Chernihiv, Kyiv, Lviv, and Zhytomyr, with plans underway to expand the model to other locations. Where the program is active, support from medical personnel has increased steadily as doctors and nurses experience firsthand how this collaboration with survivors can aid their work.

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Similar programs have existed for many years in other countries, and it is a well-established means of providing information and support to newly diagnosed women. The power of this approach lies in the survivors' inherent ability to empathize with and serve as role models for newly diagnosed patients. This effort not only has helped address the immediate psychosocial concerns of newly diagnosed women, but it has served to inform these women about the existence of community-based support groups, which many now join once they have been discharged. This program is an excellent example of the partnership that can be developed between survivors and the medical community to meet the informational and emotional needs of women with breast cancer in Ukraine. The volunteers do not seek to challenge the authority of doctors, but rather, to assist them in their efforts to provide the best care possible to women. Because the program is completely volunteer-based, it is extremely cost-effective. It only requires that medical personnel sufficiently trust the intentions and abilities of survivors in meeting with patients and that they open their doors to those volunteers offering to help.

***Forging Alliances with the Medical Community.*** A key goal of the project was to help physicians understand that addressing the psychosocial and informational needs of women—or allowing others, such as survivors or nurses trained in counseling skills, to assist in this—would facilitate, rather than hinder, their work. Indeed, the potential for mutual assistance between medical providers and breast cancer survivors is great, especially given the strained environment in which most medical providers work due to the current economic situation in Ukraine. Medical providers, in turn, can play pivotal roles in the growth of survivor and self-help groups by referring their patients to groups or encouraging them to talk with Peer Support Volunteers visiting the wards. They can also tell other professionals about the volunteer program and groups so that they, too, will refer their patients.

With this goal in mind, alliances were forged with medical providers in several important ways. First, all educational materials developed and disseminated under the project were reviewed and approved by them, as well as by groups of breast cancer patients and healthy women at risk, as appropriate. Second, efforts were made to inform them of current literature regarding the importance of integrating psychosocial care into the overall treatment plan for patients. Third, training in psychosocial care was provided to nurses and physicians in a variety of sites, as already described. Fourth, specific opportunities were created for medical professionals to interact with patients and survivors to further sensitize them to women's informational and psychosocial needs. For example, on several occasions, doctors were invited to speak to survivor groups about medical aspects of breast cancer and to answer questions. In addition, survivors are increasingly making themselves available to speak at professional meetings. The most noteworthy event in this regard was the participation of a panel of eight survivors who each presented their "stories" at the PATH Breast Cancer National Summation Conference in Kyiv in November



*Breast Cancer Survivors who participated in the panel, together with PATH team staff at the November 1999 Conference*

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1999. This was perhaps the first time that patients had been invited to participate in a medical conference in Ukraine, and for most of these women, it was the first time that they had spoken publicly about their illness.

PATH prepared a position paper outlining the role of and rationale for survivor groups as a complement to good medical care for breast cancer patients (Attachment I).

***Solidifying Organizations.*** Although most of the existing survivor groups started out modestly and informally, several have now taken steps to formalize themselves by officially registering as NGOs (in Kyiv, Chernihiv, Zhytomyr, and Kherson; the group in Lviv had done so prior to PATH's involvement). In addition, the breadth of their activity, by their own initiative, has expanded in several instances to include establishing hotlines, organizing poetry readings and art shows, seeking local sponsors, and perhaps most impressive, working towards establishing a national federation of survivor groups. In May 2000, a national conference for breast cancer survivors was convened in Kyiv, the first ever in Ukraine. This event enabled survivors from Ukraine, Poland, Russia, and the United States, as well as professionals dedicated to supporting them, to exchange information on topics ranging from self-care to political advocacy to organizational development. Most important, women with breast cancer came away feeling supported and inspired. In addition, in June 2000, leaders from groups representing eight oblasts attended a one-day training in grant-writing sponsored by the Ukrainian National Institute for Civil Leadership. In September 2000, the leaders of these groups convened again in Lviv to further develop their strategy for establishing a national federation.

To summarize, when PATH first discussed the idea of psychosocial support for breast cancer survivors—a concept little known in the country for breast cancer—there was official skepticism, but a profound expression of need on the part of individual women. Now, after only two years of PATH activity, there are eight groups concentrated in eight oblasts, and women expressing interest in three more. In short, the demand for such groups has been impressive.

In countries such as Ukraine, where current economic circumstances are extremely difficult, breast cancer survivors have started to play a valuable role, in particular, in complementing the efforts of medical providers in meeting the informational and psychological needs of other women with breast cancer. In addition, by being willing to be public about their illness, they have begun the important process of challenging long-held societal views about cancer and shattering the stigma that surrounds the disease. Finally, and perhaps most important, survivors are effective role models for newly diagnosed women by serving as living proof that they not only survived breast cancer, but have gone on to live normal, productive lives.

### **Radiotherapy Assessment and Recommendations**

At first, the PATH breast cancer project had no intention to address the area of radiation therapy. The great costs of contemporary American radiotherapy technology were beyond the possibilities of project funding, so it seemed unrealistic that any meaningful contribution could be made in this treatment area. Nevertheless, it became clear that PATH needed a better understanding of current Ukrainian approaches to radiation therapy as knowledge of Ukrainian radiotherapy practices and capability would be important for evaluating future breast cancer treatment needs. Emerging international trends in treatment, such as the earlier detection of breast cancer cases through mammography screening and a

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surge of interest in breast conservation surgery, will be impacted by the status of practice in Ukrainian radiotherapy. Accordingly, PATH conducted an assessment of radiotherapy practices.

Midway through the project, PATH contracted with consultants Dr. Karen Lindsley, radiation oncologist at the University of Washington (UW), and Dr. Alina Popescu, medical physicist at the UW, to assess the status of radiation therapy at the three project sites. Dr. Lindsley observed radiotherapy practice and reviewed treatment protocols, while Dr. Popescu brought an ion chamber and an electrometer to calibrate the Cobalt-60 radiotherapy machines. (Due to the delay in receiving the calibrating instruments which were confiscated by Ukrainian customs upon Dr. Popescu's entry into Ukraine, she was able to complete calibrations of Cobalt-60 radiotherapy equipment only in Chernihiv and Odesa.)

As a result of their assessment, the consultants concluded that the Ukrainians have the capacity to do effective radiotherapy adequate to proceed with mammography screening and breast conservation surgery. Better dosimetry monitoring, and training in doing this, could substantially improve Ukrainian radiotherapy with surprisingly low-cost additional equipment of the type Dr. Popescu had brought with her. The consultants made a series of recommendations for improving radiotherapy practice, chiefly centering on establishing a Quality Assurance program and enhancing the educational opportunities for radiotherapists and medical physicists by encouraging links to the international medical community.

Unfortunately, PATH considered it had neither the remaining project time nor the funds to develop an effective program intervention in radiotherapy. Details of the assessment and recommendations are contained in the consultants' report (Attachment J).

### **Surgical Approaches to Breast Cancer and Benign Breast Disease**

Based on early assessment findings and continuing interactions with Ukrainian surgeons, it became clear that the Ukrainian approaches both to breast cancer and to benign breast disease differed from current United States and European practice. While the evolution of our understanding of these problems is ongoing (and we are far from definitive answers), it appears that the models used in Ukraine did not reflect the results of scientific and clinical studies of the last few decades. The reigning Ukrainian surgical treatment paradigm corresponded to the teachings of the U.S. surgeon, Dr. William S. Halsted (1852-1922), who pioneered radical mastectomy surgery for breast cancer at the turn of the 20<sup>th</sup> century.

Further, the Ukrainian model of breast cancer disease treatment reflected this paradigm, namely that breast cancer begins in the breast, then spreads to local axillary lymph nodes, then to regional lymph nodes, and then on to the systemic circulation. Consistent with this belief, patients are treated before surgery with low-dose radiation in an attempt to seal the local and regional lymphatics and hinder the spread of cancer cells that theoretically might become dislodged during the subsequent surgery. Patients receive some chemotherapy prior to surgery to decrease any metastases; this is followed by radical mastectomy, or modified radical mastectomy (with preservation of some of the chest musculature), and then by post-operative radiotherapy and chemotherapy (when available).

In contrast, current practice in the United States and Western Europe reflects a much greater concern that the breast cancer cells may metastasize distally early in the course of disease, i.e., without a sequential local-regional spread first. Hence, when large palpable tumors are detected, the risk from systemic metastasis is considered much greater than the local tumor risk. Therefore, in Western

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countries, energy is focused on treating the systemic problem with higher doses of chemotherapy, and on offering a variety of approaches to treatment of the local breast tumor. This different paradigm results in different treatment approaches with regard to both early and late stage disease, but in both cases, relies more heavily on expensive chemotherapeutics.

In the later stages, which make up more than half the cases in many parts of Ukraine, surgery is the predominant Ukrainian treatment response. In the United States, these patients are evaluated with multiple diagnostic techniques to characterize the staging, and then receive chemotherapy. Stage III patients in the United States typically undergo surgery, principally for pathological evaluation of the response of the breast and lymph nodes to chemotherapy. Stage IV patients in the United States generally are not considered surgical cases at all; such patients would receive either palliative treatment, or a very aggressive chemotherapeutic approach with stem cell or bone marrow transplantation. Surgery would be reserved for those Stage IV patients who evidence complete response to the chemotherapy. However, the aggressive U.S. approaches to late-stage disease would not appear to be well-suited to the Ukrainian reality of constrained economic resources.

As screening increases the detection of earlier stage disease, there has been evidence of a willingness on the part of some Ukrainian surgeons to use breast-conserving surgery combined with radiotherapy. Where radiotherapy is constrained by outdated sources of radioactive material or poorly calibrated equipment, justifiable concerns about the risks of incomplete treatment hold some surgeons back from adopting this approach.

Early assessment also revealed divergence of Ukrainian understanding of the biological behavior of benign breast lesions from that of the United States and Western Europe. In Ukraine, benign breast lesions are more often considered to be precancerous and, therefore, require wide excision. These excisions were observed to be cosmetically deforming. International research does indeed uphold that some benign breast lesions are precancerous—e.g., atypical hyperplasia, lobular carcinoma *in situ*, and some forms of ductal carcinoma *in situ*. Most of these lesions are thought to increase the patient's relative risk for developing breast cancer, but the cancer could arise anywhere in either breast, not specifically the biopsy site alone. Therefore, doing a wide local excision does not provide a confident measure of protection from the subsequent development of breast cancer and may, unnecessarily, disfigure the woman. This different view was of concern to PATH, since an active screening program could be expected to identify many cases of benign breast disease, which might lead to many more aggressive and probably unnecessary surgical interventions.

It was clear that Ukraine's different algorithms for breast cancer and benign lesions were firmly entrenched in customary practice and were reinforced by medical care directives and the pronouncements of surgeons in official positions. PATH accordingly concluded that the project could not tackle this head-on. Therefore, our strategy was to open a dialogue which offered information on the scientific basis for the current U.S. paradigms, opportunities at the medical symposia to discuss the different approaches, and regular interaction with the consultant specialists (surgeons, pathologists, and medical oncologists) in the course of other project activities. We saw some success in this strategy: local advocates of these newer views gained greater prominence, use of breast-conserving surgery increased, and the debate within the Ukrainian medical community is now established. However, such fundamental changes in thinking will undoubtedly take time, and the financial resources to implement U.S.- and

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European-style treatments may not be available for many years. The project's focus on a preventive approach, strengthening early detection of breast cancer through appropriate screening, was considered more likely to yield early and sustainable benefits.

Major project accomplishments in the area of policy and practice guidelines include:

- A consensus emerged in support of CBE as a primary basis for a sustainable screening program in the near term, and a multi-disciplinary working group was established to follow through on the recommendations of the Early Detection workshop.
- In the pilot project, more than 4,800 women in Chernihiv were screened by mammography, and nearly 19,000 women in Chernihiv raion (more than 90% of those over 30 years) were screened by CBE in 1999 alone. While the proportion of Stage IV cases declined, the proportion of Stage I cases rose substantially. As a result of mammography screening in project sites in Chernihiv and Odesa, 193 cases of cancer were identified, of which 93 were Stage I.
- The broad principle of evidence-based medicine and the more specific concept of adequate chemotherapy dosing were illustrated. As a side benefit, clinical trial capacity was established at the Odesa Center, with concomitant income-generation possibilities and increased access to modern drugs.
- A consensus that hormone receptor tests (one of the new family of ICC methods) have an important role to play in diagnosis was established; they were recommended by Ukrainian pathologists as a priority even in the resource-constrained environment of Ukraine.
- Even in the very short time since the project activities with survivor groups began, the groups have moved beyond individual support to outreach and advocacy. Several groups have registered as NGOs, and plans for a national federation are under way.
- Even in the area of radiotherapy, there are relatively low-cost interventions that could greatly increase the quality and safety of cancer care.

Major project constraints in the policy and practice guidelines area include:

- Fundamental ideas about the nature of breast cancer and benign breast disease will be slow to change, especially since so much about the underlying biology is still uncertain.
- Financial constraints greatly limit the ability of providers to adopt new practices (especially ones requiring new equipment or expensive drugs), even when they are convinced of their value.
- The highly centralized and hierarchical process for setting policy and practice guidelines (with authority delegated by the MOH to a designated expert) provides a useful mechanism for standardizing practices, but can also impede change if the designated authority does not agree with the new ideas. While there is some room for dissenting voices to be heard and progressive clinicians to champion new ideas, the conservative views of the current Chief Mammologist hindered some of the policy changes sought by the project.

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## PROJECT MONITORING AND EVALUATION

Based on the assessment work of the first six months of the project and on consultations with the USAID project manager, Ukrainian partners, and members of the project team, a package of 42 process and outcome indicators was selected for interim monitoring and final evaluation of the project. PATH reported the progress on most of these indicators in each quarterly report; a few were reported semi-annually or only at the end of the project. In some cases, trends rather than specific numerical targets were specified because of variations in baseline levels at different project sites or the difficulty of estimating the magnitude of change that is reasonable to expect. Although these indicators do not measure all the many accomplishments of the project, we believe they highlight progress in areas that are critical to the overall goals and are suggestive of achievements in other project activities.

The 28 process indicators were divided into the five project strategy areas, as originally described in the proposal; they often represented minimum target levels that the project hoped to exceed. In fact, many were surpassed substantially. An additional four indicators addressed the number of beneficiaries of project-related services (not directly delivered by the project but reflecting the consequences of project inputs). A final eight indicators attempt to measure the impact of the project on coverage, health outcomes, or quality of care. Indicators were selected to ensure balanced coverage of the four areas (screening, diagnosis, treatment, and rehabilitation) in which the project worked.

The indicators and their final measures are given on the Project Indicators' chart in Attachment K. Comments and explanations (as needed) are given below.

### Process Indicators

***Enhance Provider Knowledge and Skills.*** The project exceeded most of the seven indicators addressing this area. For example, in addition to the three individual one-month fellowships in Seattle for pathologists, PATH assisted a radiologist from Chernihiv in successfully applying for a UICC fellowship to spend one month in Seattle studying mammography and ultrasound. Project consultants also organized a two-week study visit for a Ukrainian breast surgeon.

***Improve the Quality and Availability of Equipment and Supplies.*** The list of equipment obtained by the project is given in Attachment C. In addition to the seven pieces of major equipment (three mammography units, three film processors, one ultrasound), numerous smaller pieces of laboratory equipment were obtained, and a donation of a complete mammography unit and film processor was secured. Despite the success in obtaining equipment, chemotherapeutic drugs, laboratory supplies, and breast models for training, the project had less success in the areas of training equipment maintenance personnel or increasing the supply of breast prosthetics. Modern mammography equipment is very complex, and the special equipment service units of the former Soviet system appear to have stopped functioning when the mechanisms for transferring payments from hospitals to them disappeared. Although hospitals were able to undertake some minor repairs of equipment, it seems they will need to rely on equipment manufacturers for required maintenance and service. Instead of training personnel, the project supported a service contract for the mammography unit in the pilot screening program in Chernihiv; and a new Israeli donor (Chabad's Children of Chornobyl) has been identified to continue to support the service contract for the first post-project year, while Chernihiv seeks more permanent local funding sources. Local mammography technologists did receive quality control training in all three sites

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that will help them diagnose and correct small problems with the mammography and film processing equipment.

With regard to investigating local sources of prosthetics, PATH found only one Ukrainian company that is producing prosthetics, but declined to devote resources to enhancing production at this site. The company is located in Kharkiv; however, it was felt that the quality of their product is not very high. The company depends heavily on the government for its budget. According to regulations, women who have received a mastectomy should get free prosthetics. However, since payment is not received from the government, quality prosthetics are not manufactured. According to law, women should receive prosthetics through their workplaces, but due to lack of financial resources or the lower priority of this service, very few women get product through this method. During the regional exchanges to Poland, Ukrainian survivors were shown Polish product, and were also provided with some donated prosthetics at the end of the project.

***Increase Patient Understanding and Public Awareness of Breast Cancer.*** A participatory process involving patients and providers was employed in all three project sites when developing educational materials for patients. The project was successful in fostering collaboration between the Health Education Center in Chernihiv and the Chernihiv Center, but was less so in Odesa and Kyiv. During the final workshop on Early Detection, the idea of partnership with the Health Education Centers was included by participants as the appropriate strategy for developing and distributing educational materials, both for patients and the public.

The list of materials developed for both groups, and the numbers of each printed and distributed, is given in Attachment D. The project produced even more materials than originally hoped, and an additional audio tape for patients (on relaxation).

For the public awareness effort, PATH decided to develop three television and three radio spots (instead of five radio ads), since the baseline survey showed that television was an important source of public information in many areas. Project staff provided interviews to newspaper or magazine journalists that led to publication of 22 articles, and are aware of numerous other articles to which our project partners contributed.

A draft national IEC strategy was prepared based on the experience accumulated and was shared with the MOH. It can serve as the starting point for local planning, but it could not be finalized until more local input is obtained and a local implementing body is identified.

***Strengthen Health Infrastructure.*** The key source of data information for monitoring is from the National Cancer Registry. The financial support and technical assistance provided by PATH to the National Registry office to enable them to bring the registries in Odesa and Chernihiv up to standard was described earlier. As a result of the assistance provided, the information in the registry database on the number of cases for Odesa and Chernihiv and the stage at the time of diagnosis is now considerably more reliable. A database was also developed in the radiology unit in Chernihiv to track mammography patients.

As described earlier, it was not possible to establish an electronic system for distributing breast cancer information due to the lack of widespread access to e-mail and the difficulty of selecting and translating

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appropriate articles. The proposed new mammology association may be a good channel for disseminating information.

***Refine Policies and Practices.*** The final Early Detection workshop was the only meeting during the project that asked participants to come to a consensus about recommendations; the summary report of this meeting is given as Attachment G. In addition, three position papers were prepared: one on CBE as the recommended primary screening method, one on one-view as compared to two-view screening mammography, and one on the importance of survivor groups as a complement to medical care (see Attachments F, H, and I). PATH staff met regularly with Dr. Irkina in the MOH over the years of the project to discuss a variety of policy issues, including target age groups for screening, use of psychologists and social workers in cancer hospitals, discussion of the true diagnosis with breast cancer patients, and incorporation of CBE training into medical and nursing curricula. Perhaps due, in part, to these discussions, Dr. Irkina became a vocal and eloquent supporter of the activities and strategies of the project.

***Beneficiaries of Project-related Services.*** The total numbers of screening and diagnostic mammograms in each of the three project sites are given in the Indicators Chart (Attachment K). Screening mammography actually began in Chernihiv in the third quarter of 1998 (after the equipment was installed and training completed). In Chernihiv, the level of screening mammography increased from about 20 women each month in the six months before the start of the pilot screening program to about 195 women each month in the 24 months after (July 1998-June 2000). Depending on the season, and on whether both mammography machines were functioning, the screening level in Chernihiv has varied from a low of 105 women/month to a high of about 315 women/month. Although there was no official mammography screening program in Odesa, they also increased their level of screening mammography from an average of 9 women/month in the first nine months of 1998 to an average of about 128 women/month in the 18 months between October 1998 and March 2000 (their last reporting period).

While diagnostic mammography stayed relatively constant in Chernihiv throughout the project (using the modern machine they already had), rates of diagnostic mammography went up dramatically in both the Kyiv Institute and in the Odesa Center. In Odesa, where their previous equipment was antiquated and not always functional, diagnostic mammography more than doubled from 1998 to 1999 (659 women versus 1,397 women). In the Kyiv Institute, their old unit was not in service most of 1998, but the new unit provided by the project enabled them to provide diagnostic mammograms for about 252 women each month.

The number of Chernobyl-affected women served by the project was difficult to track. Chernihiv asked all mammography clients their status, but women receiving CBE could not be tracked for Chernobyl status. The Kyiv Institute did not have such information in their patient records either. The numbers reported on the Indicators Chart, then, primarily reflect those who were screened by mammography in Chernihiv and (to a much lesser extent) in Odesa. However, most of the women living in Chernihiv raion are considered Chernobyl-affected since this raion is adjacent to the disabled nuclear plant area, and nearly 19,000 women in the raion were documented as having had CBE in 1999 performed by medical workers who had received refresher training in CBE. The assistance given by the project in providing

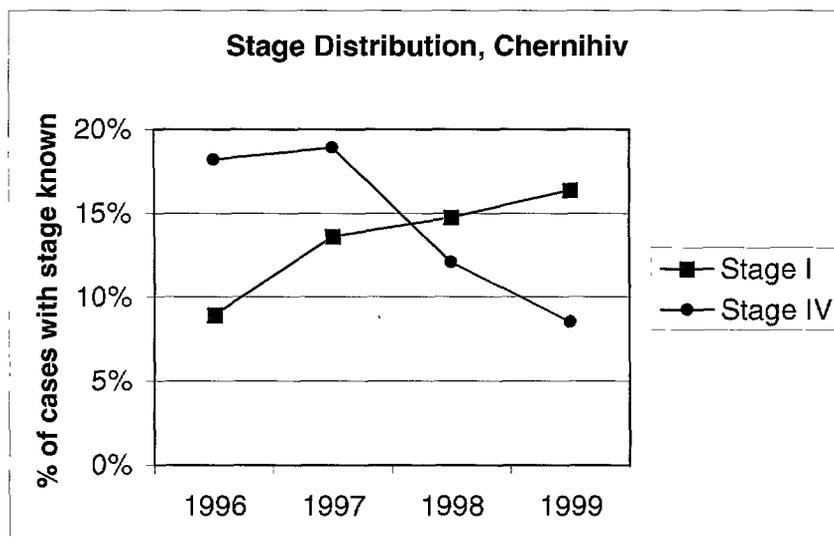
CBE and mammography training to staff in Kyiv Oblast and Zhitomyr Oblast will also have benefited Chernobyl-affected women, since their populations were heavily affected by the Chernobyl accident.

The variety of materials produced and the breadth of their distribution far surpassed our hopes in the project. It was clear, though, that there was a great need for these materials. Not only were additional topics covered beyond our original plans, but reprinting of several materials was needed because of the demand for them. In addition, PATH materials were reprinted and distributed by AIHA and by the Stevens Foundation for Russian/Ukrainian immigrants in two counties of Washington State, U.S.A.

### Impact Indicators

**Increase Early Detection.** Although the project was mainly active in Chernihiv City and nearby Chernihiv raion, it appears that the impact of the CBE training, the mammography screening, and the public information campaign is detectable even when looking at aggregate figures for the entire oblast. Figure 1 shows the proportion of cases with late-stage (Stage IV) disease at the time of diagnosis.

Figure 1



This proportion began to drop in 1998 as project activities started up; at the same time, early stage (Stage I) detection began to rise. Over the four-year period, Stage I detection increased 84%, while Stage IV disease declined by 54%. Although the classification of Stage III cases is considered less reliable, the effect is evident even when combining Stage III and IV cases, with a 24% decline in the four-year period (primarily in 1999). In Chernihiv City, where the mammography program was most available, there was a 16% increase in Stage I detection between 1997 and 1999, and a 35% drop in Stage IV detection. In Chernihiv raion, where the CBE program was most active but few took advantage of screening mammography, there was no change in Stage I detection, but a 30% decline in the proportion of Stage IV cases detected between 1997 and 1999. In comparison with some other oblasts for which the Cancer Registry has reliable stage data, Lviv also experienced a 30% reduction in

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Stage IV diagnoses during the same period, but had no increase in Stage I detection. Odesa and Zhitomyr, both of which had a lower proportion of late stage disease to begin with, saw their late stage proportions stay the same or rise slightly and had very little change in the proportion of Stage I cases detected.

Although the project had hoped to be able to measure a drop in early mortality (i.e., within a year of diagnosis), the most recent data available are for deaths in 1998 (which represent cases diagnosed in late 1997 and early 1998, before the screening program in Chernihiv was fully active). Data on cases diagnosed in 1999 (who died in 1999 or in 2000) will not be available until 2001, at the earliest. About two-thirds of such deaths occur among women whose disease is classified as Stage IV at the time of diagnosis. Therefore, since the absolute number (as well as the proportion) of cases diagnosed at Stage IV in Chernihiv declined by 49% from 1996 to 1999, one might anticipate that the early mortality might also have dropped by about 32% in the oblast.

The project set an ambitious target of coverage for screening mammography: 50% of women 45-64 years old in Chernihiv raion (which would have been 4,260 women). Although about 4,800 women were screened by mammography, they were primarily from Chernihiv City rather than the more rural Chernihiv raion. Transportation seemed to be the primary barrier, but even when a small grant was given to support fuel costs for the raion's van, the number of women referred for mammography screening remained quite low. A concerted effort to organize convenient transportation from outlying villages seems to be required to enable women to get into the city where the screening service is offered. However, screening by CBE, which is offered at the local FAP reached nearly 90% of eligible women in 1999. (To achieve 50% coverage of women ages 45 to 64 in the entire oblast with screening mammography every two years would require about 44,000 women each year to be screened. At maximum utilization rates, this would require at least seven more mammography machines.)

***Improve Quality of Screening and Diagnostic Care.*** Each of the three project sites received equipment and training for maintaining quality control of mammograms. A "phantom" is a plastic block with dense areas simulating breast abnormalities that should be detectable by mammography. Making a mammogram of a phantom provides a quick and standardized test of the performance of the mammography and film processing machines at particular settings and guides the technologist in adjusting the settings or technique. Use of the phantom and recording of the results varied from site to site. In Chernihiv and Odesa the phantom is used once a month to validate machine performance; adjustments are made in between as needed. Records on the results of the validation tests were not available. The Kyiv Institute has not been using the phantom regularly, citing a shortage of film, but the Kyiv City Diagnostic Center borrows it periodically to check their mammography equipment. All three sites reported anecdotally that the quality of their mammography has improved dramatically as a direct result of the project, because of the modern mammography and processing equipment provided, with experience using proper mammography-grade film (instead of the regular x-ray film used previously), and the training received by technologists.

It was observed during the initial assessment that a high proportion of needle biopsies were rated as non-diagnostic, either because they were not handled properly when they were taken or because they missed the suspicious area. After providing several surgeons with a training seminar on ultrasound-guided needle biopsy, we expected to see some reduction in the proportion of non-diagnostic biopsies.

The proportion in Chernihiv bounced around from a low of 4.7% in the quarter immediately after the training to a high of 34.1% in mid-1999. The average for the first half of 2000 was 27.6%. Based on discussion with the pathologist in Chernihiv, it seems that biopsies are taken by a variety of staff. Polyclinic staff rotate on a quarterly basis, accounting for much of the variation. The surgeons trained in use of ultrasound guidance have indeed, according to the pathologist, experienced a significant reduction in the number of non-informative needle biopsies. They have also begun to perform core needle biopsies (considered to be more reliable). In Odesa, the rate also varied, but in a narrower (and lower) range, from a low of 5.8% to a high of 19.8%. In the final quarterly report (April 2000) the rate in Odesa was 7.8%. A senior pathologist outside Odesa has suggested that the lower rate in Odesa is due in part to a different use of terminology.

***Increase Psychosocial Support and Enhance Patient Well-being.*** In a baseline and follow-up survey done in the project areas among providers working with cancer patients, there was clear evidence of a shift in clinician attitudes and self-reported practices. The surveys are discussed in more detail below, but a few relevant findings indicate that there was an increase in the proportion of clinicians who rated psychosocial support as a important aspect of care and who knew more about how to do it (see Table 2).

**Table 2. Oncology Doctor and Nurse Attitudes and Practices Regarding Psychosocial Support**

	Baseline (n=49)	Follow-up (n=52)
Always or mostly encourage patient to talk about her fears	38%	72%
Believe women prefer to talk with other survivors	14%	46%
Believe women prefer to talk with a nurse	0%	15%
Encourage patients to talk with survivors	2%	49%
Encourage patients to talk with family	18%	35%
Believe survivors should be trained to give support	0%	62%

An informal survey of about 40 patients or survivors was undertaken in Kyiv, Chernihiv, and Zhytomyr (where many PATH materials were distributed). When asked what was most valuable about the patient materials, the most common response was that the materials gave practical advice and recommendations about how to live after surgery. Many observers have reported marked changes in patient/survivor knowledge, primarily as a result of the print materials and the interactions with other survivors. The materials on lymphedema were particularly appreciated, as much of the information in them was also new to the nurses and doctors. Two examples of this were shared by survivors. One of the Kyiv survivors recounted that when she was visiting a friend of hers in the hospital after breast cancer surgery, she noticed that a nurse who came to the ward was going to take blood from her friend's arm on the operated side. She stopped the nurse from doing this and showed her the PATH brochure with its precautions about this practice. It seems this nurse simply did not know about this recommendation before. A survivor in Chernihiv reported that she learned from the PATH brochures that she should wear long sleeves to protect her arm from sun exposure when working in her dacha. It was new information that no one had told her about before.

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## Baseline and Follow-up Surveys

In addition to routine tracking of the project indicators, PATH carried out three surveys at the beginning and end of the project. One measured women's attitudes and practices with regard to breast cancer screening in Chernihiv, where the pilot screening program was carried out. One measured attitudes and practices related to early detection among general medical workers, while the third examined attitudes and practices related to breast cancer care among doctors and nurses in cancer hospitals. Most of the information collected in the baseline surveys was used in planning project activities, but some questions were repeated in the follow-up surveys to measure possible changes.

***Women's Attitudes and Practices with Regard to Screening.*** The baseline survey was conducted in Chernihiv, with women age 30 and older drawn from among patients, family members, and staff at the Chernihiv raion polyclinic, several health posts (FAPs), and the Chernihiv city polyclinic; family members, and visitors (but not patients or staff) at the cancer hospital and its polyclinic; and clients, accompanying family members, and staff at the pension office. The proportions from each source varied slightly from baseline to follow-up, but consisted of approximately 40% each from raion and city health facilities, 15% from the cancer hospital, and 5% from the pension office. Data for the baseline survey were collected in the second quarter of 1998, and follow-up surveys were conducted in April 2000. When comparing the 446 women who responded to the baseline survey with the 483 respondents to the follow-up survey, they are similar in their rural/urban distribution (56% vs. 57% urban) and similar in their age overall (48.7 years on average vs. 49.2 years). However, the urban group had a disproportionately high proportion of young women 30-39 and low proportion of older women 60+ (34% and 16%) in the baseline survey, which became more equal in the follow-up survey (20% and 22%, respectively). The rural group was fairly evenly distributed between the four age groups at baseline and at follow-up, although women 50-59 increased somewhat (from 24% to 30%).

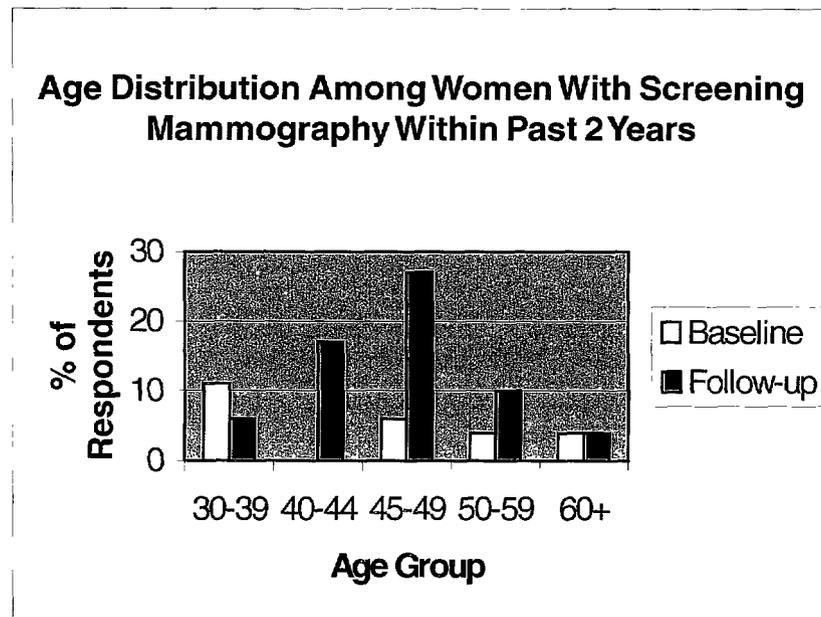
The questions asked were about prior CBE and mammography experience, willingness to undergo screening, and sources of information about breast cancer screening. The main changes are summarized in Table 3 and Figure 2 below.

**Table 3. Chernihiv Women's Attitudes and Practices Related to Screening**

	Baseline (n=446)	Follow-up (n=483)
Prior CBE experience	79%	70%
If no prior CBE, would be willing—overall	81%	96%
If no prior CBE, would be willing—women 60+	48%	97%
If no prior CBE, would be willing—rural women	65%	95%
Recent screening mammography (within past 2 years)	6%	12%
Recent screening mammography (within past 2 years)—urban women	13%	20%
Recent screening mammography (within past 2 years)—rural women	6%	6%
Newspaper as source of information on breast cancer	42%	29%

The most striking findings were the doubling in “recent” mammography screening and the increases among older women and rural women in willingness to consider having CBE (among those who had not previously had it done). As expected, the gain in screening mammography was seen primarily in the urban women, probably because of their easier access to the unit. The slight drop in reported CBE experience was a surprise, but it may be explained, in part, by the shift in age distribution from the baseline to follow-up surveys. Younger women were more likely to have had CBE and were more heavily represented in the baseline than the follow-up survey. The decline in use of the newspaper as a source of information was most noticeable among rural women and may have been due to problems of access. The distribution of screening mammography among the age groups, as seen in the figure, was much improved at the follow-up survey, since women in their later 40s and 50s (who would benefit the most from mammography) showed the most increase.

Figure 2



There was not much change seen in attitudes toward mammography among those who had not yet had it (about 80%-85% of women not yet screened were willing), nor much change in sources of information other than newspapers. Television continued to be the primary source cited, with radio and newspapers next for most groups. Women 40-49 were more likely to mention posters as a source of information in the follow-up survey (28% at baseline vs. 34%).

**Health Worker Attitudes and Practices Regarding Early Detection.** Respondents to this set of surveys were gynecologists, midwives, and “theraputists” (outpatient clinic doctors) from polyclinics and health posts in Kyiv and Chernihiv. Data for the baseline survey were collected in the second quarter of 1998, and follow-up surveys were conducted in August 2000. While the 82 respondents of

the baseline survey included a good mix of practitioners, the follow-up survey had fewer respondents (n=48) and was predominantly gynecologists (77%). However, the age distribution between the two groups and the proportions involved in general outpatient care and routine examinations were similar.

The surveys asked about training for and practice of CBE, attitudes toward and practices related to mammography and breast self-exam (BSE), and information sources for women about breast cancer early detection. The main changes are summarized in Table 4 below, with a focus primarily on gynecologists, since other groups had limited representation in the follow-up survey.

	Baseline (n=82)	Follow-up (n=48)
Currently do CBE in routine annual women's visit—gynecologists	66%	82%
Do 20 or more CBEs per week—gynecologists	32%	69%
Have received formal training in CBE—gynecologists	64%	73%
Had enough CBE training—gynecologists	50%	58%
Have ever recommended screening mammography	51%	83%
Believe women won't comply with mammography referral	45%	2%
Recommend BSE be done once a month	66%	92%
"Totally disagree" that women will not heed advice about BSE	50%	60%
Believe survivors would be good for delivering messages about early detection to women	27%	48%
"Totally disagree" that talking with women about breast cancer will just scare them	43%	48%

**Table 4. Health Worker Attitudes and Practices Related to Early Detection**

There was an increase in the reported performance of CBE, both in the number of gynecologists reporting doing it as a part of routine annual visits and in the number doing 20 or more each week. Although more than 90% of all baseline respondents said they did CBE at least occasionally, the frequency climbed after the training offered by the project and the public awareness campaign. There was a modest increase in the number reporting that they had received formal training in CBE and that it was sufficient. Since the training was focused initially on Chernihiv raion (which has fewer than 20 gynecologists), some of the doctors in the follow-up survey apparently come from areas that have not yet received the new CBE training. Without funds for special training sessions, the CBE module will have to be incorporated in regularly scheduled updating training which doctors attend once every five years. At that rate, it will take three to four more years to reach all doctors in the oblast.

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The survey shows a substantial increase in the number of health workers recommending screening mammography, while the number who doubted women's willingness to comply with such recommendations correspondingly fell off sharply. The proportion of health workers who believed that BSE is a somewhat or very effective screening method was greater than 90% at baseline and remained high. However, the number of health workers who knew that BSE should be done monthly went up a little, along with a modest increase in the number of doctors who believe that women will take BSE advice seriously. Since the project did not emphasize BSE heavily (given the lack of evidence in support of it), it is not surprising that there was not a significant change in this.

There was a shift in attitudes about talking with women about breast cancer. At the end of the project more doctors were convinced that such talk would not just scare women; they also were much more receptive to the idea that breast cancer survivors would be good candidates for delivering the message about screening to other women. Opinions about other groups who could deliver this message did not change much (e.g., more than 90% thought that gynecologists were appropriate for giving screening advice to women at both baseline and follow-up). Awareness of efforts to inform women about breast cancer was already high at baseline and did not change much at follow-up (87% vs. 90%).

***Health Worker Attitudes and Practices Related to Breast Cancer Patient Care.*** The baseline survey was conducted among doctors and nurses in the oncology hospitals in Chernihiv and Odesa, while the follow-up survey was carried out with similar staff at oncology hospitals in Chernihiv and Kyiv. Data for the baseline survey were collected in the second quarter of 1998, and follow-up surveys were conducted in July 2000. There were several differences between the two samples. Data from Odesa were not available for the follow-up survey; however, most of the psychosocial work was done in Chernihiv and Kyiv, and there were no indications that Kyiv and Odesa differed substantially at the baseline. While the 49 respondents of the baseline survey included about 25% nurses (with the rest being doctors), the follow-up survey (n=52) had only 10% nurses. The age distribution between the two groups also varied, with the follow-up survey population being considerably younger than the baseline group (nearly twice as many who were younger than 40 years in the follow-up population). Because of these differences, it is hard to be sure whether differences between baseline and follow-up values are due entirely to real changes or partly to the differences in the two samples, so conclusions must be drawn cautiously.

The questions asked were about the type of psychosocial support available to patients, the amount of information given to patients about diagnosis and treatment, whether or not to tell women their cancer diagnosis, training received and strategies used for supporting patients, who should receive training, and what types of public information are available on breast cancer. The main changes are summarized on Table 5 and Figure 3 below.

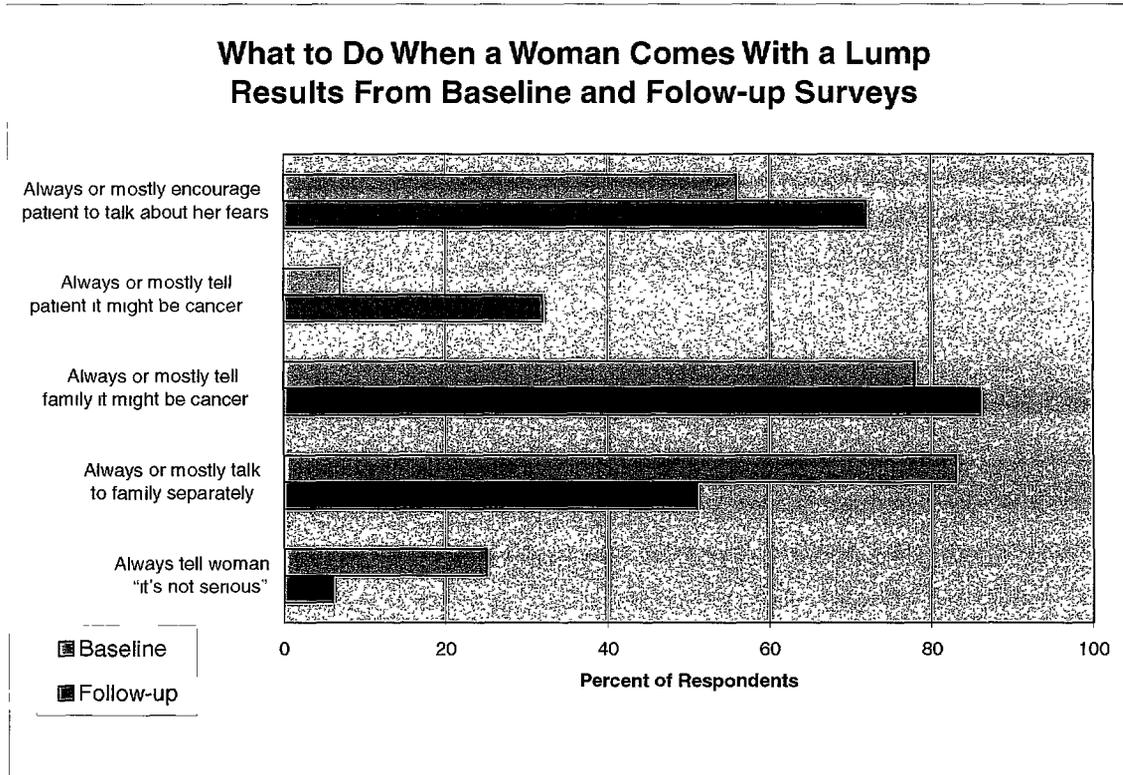
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**Table 5. Health Worker Attitudes and Practices Related to Patient Care**

	Baseline (n=49)	Follow-up (n=52)
Counseling available for patients after discharge—group	0%	19%
Counseling available for patients after discharge—informal	35%	48%
Know of survivor support groups	0%	67%
Believe women feel better after talking with survivors	14%	46%
Believe women feel better after talking with husband	8%	12%
Believe women feel better after talking with counselor	0%	10%
Encourage women to talk to survivors	2%	44%
Encourage women to talk to family	18%	35%
Discourage women from talking to survivors (doctors only)	24%	4%
Believe survivors should be trained to give support	0%	62%
Believe women don't want the truth	35%	23%
Give diagnostic information to 50% or more of patients	36%	62%
Help women feel better emotionally by prescribing medication (Chernihiv only)	25%	10%
Invite patients to ask questions about their treatment (doctors only)	46%	60%

Acknowledging the limitations of the data noted above, it appears that there has been a definite shift of attitude and behavior on the part of medical workers in the project areas. They are much more likely to be more open with patients (at least according to their self-reported behavior) and are more likely to recognize the value of people other than medical workers in offering emotional support to women. They are more likely to give information and less likely to rely on medication to calm patients; they are significantly more likely to know about and support the role of survivor groups for peer support. To be sure that these changes in reported attitudes and beliefs are translated into changed behavior, it would be necessary to interview patients, but this was not feasible with the resources available to the project.

Figure 3



Both the indicators tracked during the project and the three special surveys done at baseline and near the end of the project provide useful evidence that the project achieved some notable successes. Skills were enhanced and applied, attitudes and behaviors changed, and knowledge about breast cancer and the value of early detection increased among several important groups. The evaluation data, even with their acknowledged limitations, were helpful both during the course of the project (helping staff monitor progress and identify areas that were lagging) and at the end (assessing where the most notable achievements were and where work remains).

## COST-SHARE CONTRIBUTIONS

PATH was able to leverage USAID funding by raising US\$413,354 in direct donations and in-kind contribution of goods and services from non-federal sources. This exceeded the required contribution (\$263,440) by 57 percent. The breakdown of contributions is as follows:

Category	Amount	Percent of Total
Consultant time and other services	\$249,560	61%
Equipment and supplies	\$126,024	30%
Donated registration fees for education	\$ 4,880	1%
Donations by companies	\$ 6,682	2%
Donations by individuals	\$ 16,233	4%
PATH internal funds	\$ 9,975	3%
Total	\$413,354	100%

These contributions were instrumental in achieving project objectives; however, of particular note are the donations of pathology equipment and supplies (mostly free or at significant discounts) and certain expert services—the trainer in mammography technique, and the pathologist trainers. Our consultative group was extremely generous in their donation of time, as well as linking us to critical suppliers.

At the beginning of the project, PATH envisioned it could obtain discounts or reduced prices for pharmaceuticals for treatment purposes. Rather, we discovered fairly early on that the drugs we wanted for treatment protocols were not registered for importation or use in Ukraine, and/or the companies were reluctant to provide them to this new market.

The individual cash donations received were primarily used to facilitate the startup and sustainability of breast cancer survivor support groups. The funds were distributed to six different groups in six different oblasts. The groups expressed much appreciation for this financial support, which assists greatly with cost items such as communications, publicity, office space, and printing materials.

## LESSONS LEARNED

The following summarizes the more important lessons learned from implementing this project, particularly in the areas of early detection, clinical care, and psychosocial support.

### Early Detection

- Early detection of breast cancer depends on a combination of public awareness, appropriate screening methods, timely referral for appropriate diagnosis and treatment, service organization, and monitoring and evaluation. These elements can be realized in Ukraine, as demonstrated by this project.
- Screening mammography is not cost-effective or sustainable with Ukraine's current resources. Ukraine will need to rely on CBE to promote early detection, and devote current mammography resources to diagnosis of suspected breast disease.
- More modern mammography equipment is essential for Ukraine, even to meet current diagnostic needs.

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## **Clinical Care**

- Medical approaches from other areas should not be adopted without careful analysis of their appropriateness to the Ukrainian situation. Differences in clinical practices in Ukraine from those in the United States stem partly from underlying differences in treatment approach and philosophy, partly from limited access to recent international scientific literature, and partly from constraints in availability of newer diagnostic technology and medical and surgical treatment.
- A team approach to clinical care is feasible and cost-effective within Ukraine. Continuity of personnel and strategy are essential when dealing with complex health problems like breast cancer. Effective clinical intervention depends upon the coordination of services in reliable pathology, appropriate surgical care, chemotherapy, and radiotherapy.

## **Psychosocial Support**

- Most breast cancer patients want to be told their diagnosis. Although Ukrainian physicians still don't always tell patients that they have cancer, PATH learned through focus groups and in-depth interviews that many patients know their diagnosis and want to communicate more openly with health care professionals about their disease. Working from that information, PATH was able to catalyze change, promoting psychosocial support among breast cancer survivors.
- Progress in psychosocial support for breast cancer survivors depends on proceeding from a solid scientific basis, facilitating the nascent efforts of the women themselves, and linking the survivors with established international groups.
- Survivor groups are a cost-effective and acceptable support mechanism in Ukraine.

## **Regional Links**

Links with neighboring countries in the region provide useful and relevant experience and knowledge. Ukrainians have developed contacts and growing connections with colleagues and volunteer partners from Poland, the Czech Republic, Russia, and Belarus. Encouragement of regional activities is strategically effective, because the people of the region have experienced common problems and organizational structures in recent history.

## **FOLLOW-ON NEEDS**

The following areas of need were identified during the project, and remain to be fully addressed as the project closed:

### **Medical Training and Education**

A more sustained effort in specialty training than PATH could provide in this project is needed for all the relevant health care workers—whether pathologists, radiologists, mammographers, oncologists, surgeons, or psychologists. In addition, for more sustainable impact on medical education, a more direct and comprehensive intervention strategy focusing on medical educators in the medical schools and postgraduate training settings is needed.

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However, barring a larger sustained approach aimed at strengthening medical training institutions, shorter-term training in focused subject areas with carefully selected and well-motivated trainees can be effective. Moreover, the syllabuses and didactic materials can be offered to medical training institutions for adoption into their standard curriculum. Medical leadership should be encouraged to establish working groups addressing standards of practice and continuing education. Greater connection with international professional organizations and peer groups, such as European Society for Medical Oncology (ESMO), American Society for Clinical Oncology (ASCO), and UICC, can be encouraged or subsidized to strengthen collegiality and encourage the exchange of knowledge and experience.

Access to Internet resources should be encouraged. Effective access will become easier as more computer capacity and Internet connectivity become available in Ukraine. However, to take fuller advantage of the Internet, more English language competence is needed among practitioners. Ukraine lacks broad access to modern medical textbooks and literature. However, access to information, whether through the Internet or printed literature, is not only a resource issue, but also an issue of long-established impediments to all kinds of technical information exchange.

For now, professional meetings and symposia seem to be the best method for exchanging information to selected trainees in Ukraine. The proposed new association on breast diseases may be a good educational channel.

### **Equipment and Supplies**

Ukraine is in need of more mammography machines to meet its needs for diagnosis. Mammography also requires ongoing expenditures and a reliable, trained infrastructure of maintenance service. Similarly, immunocytochemical pathology techniques require funding and access to imported consumable supplies. Covering these costs depends on stable, predictable reimbursement mechanisms.

### **Quality Control for Mammography, Radiotherapy, and Pathology**

Opportunities for establishing quality control systems in the fields of mammography, radiotherapy, and pathology were identified during this project. Further expansion of these efforts are needed to embed the practices and expand the quality control systems.

### **Support for Maintaining Regional Linkages**

Newly-formed NGOs such as are emerging among the psychosocial support groups could benefit from financial support for maintaining connections with collaborating organizations in neighboring countries, enabling travel and communication opportunities to be expanded.

### **Training and Organizational Support for Survivor Groups**

The growing network of breast cancer survivor psychosocial support groups need ongoing support for training of volunteers and maintaining their organizations. They need contact with international foundations and NGOs with an interest in this area.

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## CONCLUSIONS

### Objectives Achieved

The PATH Breast Cancer Assistance Project has helped establish a solid basis for modernizing breast cancer control in Ukraine. The project has increased awareness of the importance of early detection of breast cancer and demonstrated the methodological components needed to increase early detection. By the detection of breast cancer at the earlier, more curable stages, gains in survival rates may be expected as a result of effective treatment of earlier stage disease.

In addition, the project exposed health care professionals to major clinical advances in breast cancer control strategies through educational workshops, symposia, conferences, and training fellowships.

One of the more successful components of this project was developing psychosocial support activities for breast cancer survivors. As a result, the stigma of the breast cancer diagnosis and the fear of death from breast cancer have diminished, as survivors gain strength and empowerment from peer support and from more open communication with their care givers.

Also, they gained confidence and courage to speak openly about their feelings, their fears, and their wishes. Women in several cities have been featured in national and oblast news articles in which they have openly described their stories. They understand how important their role is in educating the public, in general, and women at risk in particular, about the importance of early detection.

### Chief Sustainable Elements

There are good reasons to think that many of the project achievements are sustainable beyond the life of the project. All the training activities of the project represented investments in *human capacities* that will last long after the project's end. In addition to the many individual learning experiences and acquisition of new skills and new ideas, the master trainers in CBE and mammography technology are prepared to pass on new skills to additional colleagues over the coming years. Health workers, patients, and the general public were all exposed to new ideas that will influence their perceptions and attitudes for years to come. Specific *tools* like the various curricula, learning aids (e.g. breast models), print and audiovisual materials (such as the brochures and TV spots), and equipment (medical, audiovisual, and computers) will remain in use and continue to provide benefit. The fact that several of the training modules have been formally incorporated into medical and nursing school curricula bodes well for their lasting impact. The establishment of *institutional structures* like the survivor groups that have registered as NGOs and the Early Detection working group, the strengthening of the cancer registries, and the development of the clinical trials capacity in Odesa represent achievements that are embedded in Ukrainian structures that have a life of their own.

### Benefits Beyond Breast Cancer

In addition to the significant achievements the project had in improving breast cancer care, many of the activities and practices introduced and encouraged by this project have attributes with immediate carry-over and relevance to other areas of Ukrainian health care. As such, they apply to and bolster the favorable outcomes of USAID's Strategic Objective 3.2 as part of its Intermediate Result 3.2.1 (improved health care services delivery). Some of the most important of these items are the following:

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- Survivor/patient support group methodology could be useful for other groups, for example, patients living with AIDS.
  - Changing the doctor-patient interaction to incorporate informed patient involvement is good for all patient care and could be useful with others where compliance with treatment is challenging. One increasingly prominent example in Ukraine is tuberculosis control.
  - A multidisciplinary team approach to clinical care is essential in modern medicine. Increasingly complex clinical problems depend on a free flow of information among health care workers to achieve effective responses.

The success of this project is due not only to the work of the entire PATH team and our Ukrainian partners, but to all the individual medical workers, patients, and community members in Ukraine who opened their minds to consider new possibilities and contributed their ideas and efforts towards our common goal of helping to reduce the impact of breast cancer on the women of Ukraine. That same commitment and creativity could be applied to many other health problems with which Ukraine is currently struggling.

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RDRP15601 folder  
12/2000

**Attachment A**  
**Ukraine Breast Cancer Assistance Project**  
**Project Team**

**Ukraine Breast Cancer Assistance Project  
Project Team**

Seattle Breast Cancer Team

Roscius N. Doan, M.D., M.P.H.	Project Director
Vivien Davis Tsu, Ph.D.	Deputy Project Director
Amie Bishop, M.P.H., M.S.W.	Program Officer
Barbara Crook, M.S.W.	Program Officer
Todd Dickens	Senior Procurement Officer
Kristin Bedell	Project Administrator
Svitlana Okromeshko	Program Associate
Susan Franco	Program Assistant

Kyiv Breast Cancer Team

Yekaterina (Katya) Gamazina, M.D.	Project Manager
Elena Kononova	Program Associate
Alla Kovtun	Program Associate

Ukrainian Consultants

Svetlana Karpilovskaya, Ph.D.	Consultant, Psychologist
Tetiana Khokhlich, M.D.	Consultant, Psychosocial Training
Galina Mastruk, M.D.	Consultant, Gynecologist-Oncologist
Natalya Suprun	Consultant, Psychosocial Support Activities

U.S. Consultants

Benjamin O. Anderson, M.D.,	Assistant Professor of Surgical Oncology, Department of Surgery, University of Washington
Bella August, M.S.W.	Psychologist, Private Practice
Richard B. Clarfeld, M.D.	Surgeon, Providence Breast Cancer Program, Polyclinic
Allen Gown, M.D.	Director, PhenoPath Laboratories

Julie R. Gralow, M.D.	Assistant Professor, Department of Medical Oncology, University of Washington
Charlene P. Holt, M.D.	Independent consultant; formerly Director, Women's Health Initiative, Madigan Army Medical Center; Project Director, Department of Defense Breast Cancer Prevention, Education, and Detection Program
Cary Kaufman, M.D., F.A.C.S.	Director, Bellingham Breast Center
Leslie Jacobson, M.S.	Psychologist, Private Practice
Constance Lehman, M.D., Ph.D.	Assistant Professor, Department of Radiology, University of Washington; Director of Breast Imaging, Seattle Cancer Care Alliance
Frances Marcus Lewis, R.N., Ph.D., F.A.A.N	Professor, University of Washington, School of Nursing
Karen Lindsley, M.D.	Associate Professor, Department of Radiation Oncology, University of Washington Medical Center
Louise Miller, R.T.R.M.	Independent Mammography Consultant
Odette Petersen	Coordinator, SHARE (Self Help for Women with Breast or Ovarian Cancer)
Alina Popescu, Ph.D.	Medical Physicist, Department of Radiation Oncology, University of Washington Medical Center
Steve H. Taplin, M.D., M.P.H.	Assistant Professor, University of Washington; Director, Department of Preventive Care, Group Health Cooperative of Puget Sound
David B. Thomas, M.D., Ph.D.	Professor and Head, Program in Epidemiology, Fred Hutchinson Cancer Research Center
Hadi Yaziji, M.D.	Pathologist, PhenoPath Laboratories

**Attachment B**  
**Ukraine Breast Cancer Assistance Project**  
**Project Training Events**

**Ukraine Breast Cancer Assistance Project  
Project Training Events**

**External Learning Opportunities**

Breast Cancer Study Tour to Seattle	October 1997
Pathology Technician Attends First European Breast Cancer Conference in Florence	September 1998
Pathology Fellowship in Immunocytochemistry (ICC) in Seattle	November 1998
Medical Delegation Visits Polish Specialists in Warsaw	August 1999
Pathology Fellowship in ICC in Seattle	October 1999
Ukrainian Health Workers and Breast Cancer Survivors Visit Warsaw	October 1999
Breast Cancer Surgical Study Visit in Seattle (cofunded)	April 2000
Mammography Fellowship in Seattle (cofunded)	August 2000
Breast Cancer Surgeon Attends Second European Breast Cancer Conference in Brussels (cofunded)	September 2000

**Skills Workshops**

First CBE Seminars for Trainers of Trainers (TOT)	November 1997
Hormone Receptor Test Training in Kyiv and Odesa for Lab Technicians	April 1998
Mammography Seminar and Ultrasound-Guided Biopsy Training	June 1998
Mammography Positioning and QC Training in Kyiv and Odesa	June 1998
Chemotherapy Technical Assistance Consultation	July 1998
Second CBE Seminars for TOT	October 1998
Screening Mammography Workshop for Radiologists	June 1999
Radiotherapy Assessment Visit	September 1999
Pathology Technician Training in ICC	November 1999
Ukrainian Trainers Conduct 60 CBE Trainings for 1,127 Trainees	Nov 1997 - Nov 1999
Screening Mammography Workshop for Radiologists	September 2000
Mammography Positioning and QC Training	September 2000

**Medical Symposia and National Summation Conference**

Kyiv Symposium on Management of the Breast Mass	April 1998
Odesa Breast Cancer Symposium	April 1999

Breast Cancer National Summation Conference	November 1999
Early Detection Workshop: Screening Strategies and Lessons Learned	September 2000

**Psychosocial Support Training**

Conference with Ukrainian Clinicians on Psychosocial Topics	April 1998
Psychosocial Support and Patient Care Training Workshops	September 1998
Psychosocial Training Workshops in Chernihiv and Kyiv	February 1999
Seminars for Survivors in Kyiv and Chernihiv	May 1999
Peer Psychosocial Support Training in Chernihiv and Kyiv	September 1999
Kyiv Symposium on Breast Cancer Psychosocial Support	May 2000
Training of Nurses in Psychosocial Care in Kyiv	August 2000
Psychosocial Support Volunteer Trainings Conducted in 4 Oblasts	January-Sept 2000

**Attachment C**

**Equipment and Supplies Purchased and Donated**

**Ukraine Breast Cancer Assistance Project  
Equipment and Supplies Provided to Project Sites**

12/22/00

***Purchased with USAID/PATH Funds***

Type	Item/Supplier	Date Purchased	Destination	Expenditures
<b>EQUIPMENT</b>				
	GE 600T Mammography Machine	Mar-98	Kyiv Institute	\$48,000
	GE 500T Mammography Machine (reconditioned)	Mar-98	Odesa	29,000
	GE 500T Mammography Machine (reconditioned)	Mar-98	Chernihiv	23,000
	Kodak M35M Film Processors (3)	Mar-98	Kyiv Institute, Odesa, Chernihiv	38,079
	Densitometer	Jul-98	Chernihiv	425
	Sensitometer	Jul-98	Chernihiv	425
	Phantoms (3)	Nov-98	Kyiv Institute, Odesa, Chernihiv	2,070
	Mammography Machine Bucky	Feb-99	Chernihiv	4,415
	Mammography Machine compression plate & mounting arm	Feb-99	Chernihiv	1,014
	Mammography Machine compression plate & mounting arm	Aug-00	Odesa	1,407
	Computers with software, printers, modems (3 sets)	Aug-97	Kyiv Institute, Odesa, Chernihiv	5,821
	Fax machines (3)	Aug-97	Kyiv Institute, Odesa, Chernihiv	1,050
	Modem (1)	1997	Nat'l Cancer Registry	79
	Printer	Dec-98	Chernihiv	146
	Computer with software	Dec-98	Chernihiv	640
	Slide Projector	Dec-97	Odesa	1,195
	VCR & TV for training	Dec-97	Chernihiv	553
	Training Room Accessories	Dec-97	Chernihiv	585
	VCR & TV for training	Apr-98	Odesa	507
<b>SUPPLIES</b>				
	Breast models (28)	1997-1998	Kyiv Institute, Odesa, Chernihiv	3,649
	Film Processor Chemicals	Jun-98	Kyiv Institute, Odesa, Chernihiv	781
	Film Processor Chemicals	May-99	Chernihiv	1,390
	Mammography Film and Chemicals	May-99	Odesa	1,061
	Mammography Film and Chemicals	Jul-98	Chernihiv	5,140
	Mammography Film and Chemicals	Jul-99	Chernihiv	2,963

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**Purchased with USAID/PATH Funds - continued**

Type	Item/Supplier	Date Purchased	Destination	Expenditures
	Mammography Film	Jul-99	Chernihiv	3,257
	Mammography Film and Chemicals	Mar-00	Chernihiv	5,005
	Chemotherapy Drugs-Cytoxan	Apr-98	Odesa	1,806
	Chemotherapy Drugs-Adriblastina	Apr-98	Odesa	12,888
	Drug cerucol for chemo study	Jul-98	Odesa	200
	IV supplies for chemo study	Nov-98	Odesa	333
	Antibodies - Dako	Nov-99	Chernihiv, Kyiv City Center, Lviv	2,355
	Antibodies - Phenopath	Nov-99	Lviv	1,040
	Mouse Antibody	Jan-99	Chernihiv, Kyiv City Center, Lviv	217
	Pathology (ICC) supplies and reagents	Oct-99	Chernihiv, Kyiv City Center, Lviv	3,247
	Laboratory supplies: slides, stains, pipettes	Apr-98	Chernihiv, Kyiv City Center, Lviv	1,528
	Laboratory steamers (3)	Apr-98	Chernihiv, Kyiv City Center, Lviv	120
	Transformers (12) & power supply	1998-2000	Chernihiv, Kyiv City Center, Lviv	2,087
	Microwave ovens (3)	Oct-99	Chernihiv, Kyiv City Center, Lviv	586
	<b>Total Value</b>			<b>\$208,063</b>

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**Ukraine Breast Cancer Assistance Project  
Equipment and Supplies Provided to Project Sites**

***Donated through In-Kind Contributions***

Type	Item/Supplier	Date Purchased	Destination	Expenditures
<b>EQUIPMENT</b>				
	GE 600TS Mammography Machine (reconditioned)	2000	Kyiv City Diagnostic Center	19,500
	Kodak M35M Film Processor (reconditioned)	2000	Kyiv City Diagnostic Center	7,500
	ATL Ultramark 4 B&W Ultrasound (reconditioned)	2000	Chernihiv	5,000
	Olympus Stereo Microscopes (3) & accessories	1997	Kyiv Institute, Odesa, Chernihiv	4,350
	Microtome (reconditioned)	1999	Kyiv City Center	2,250
	Tissue Processor (reconditioned)	1999	Kyiv City Center	2,500
	Tissue Processor (reconditioned)	1999	Chernihiv	2,250
	Embedding Center (reconditioned)	1999	Kyiv City Center	3,400
	Waterbath (reconditioned)	1999	Kyiv City Center	200
	Pathology lab equipment spare parts & accessories	1999	Chernihiv, Kyiv City Center, Lviv	3,493
	Densitometers (2)	1998	Kyiv Institute, Odesa	1,700
	Sensitometers (2)	1998	Kyiv Institute, Odesa	1,700
	Propaq Pulse Oxymeters (2)	1997	Kyiv Institute, Odesa	13,644
	Accessories for pulse oxymeters	1997	Kyiv Institute, Odesa	979
	Oxygen sensors for oxymeters	1997	Kyiv Institute, Odesa	400
	AO Microscope with fluorescent illuminator	2000	Lviv Medical Univ.	1,895
	Mammography Machine Bucky	1998	Odesa	1,000
	Computer from PATH office (used)	1998	Ministry of Health	800
	Computer from PATH office (used)	1998	National Cancer Registry	100
	Computer from PATH office (used)	1999	Kyiv City Center	200
	Computer from PATH office (used)	1999	Chernihiv Raion Polyclinic	200
	Computer from PATH office (used)	1999	Kyiv City Diagnostic Center	200
<b>SUPPLIES</b>				
	Dako Hormone Receptor Kits	1998	Kyiv Institute	3,288
	Dako Hormone Receptor Kits	1999	Chernihiv, Kyiv Inst, Kyiv City, Odesa	5,639

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**Donated through In-Kind Contributions - continued**

Type	Item/Supplier	Date Purchased	Destination	Expenditures
	Antibodies for pathology labs	1999	Chernihiv, Kyiv City	368
	Chemicals for pathology labs	1999	Chernihiv, Kyiv City, Odesa	336
	Biopsy guns (11) and needles (77)	2000	Chernihiv, Kyiv City	2,547
	Film cassettes (9) - (used)	1998	Chernihiv, Kyiv Inst, Kyiv City, Odesa	1,800
	Film cassettes (9) - (used)	1998	Chernihiv, Kyiv Inst, Kyiv City, Odesa	1,800
	Film cassettes (23) - (used)	1998	Chernihiv, Kyiv Inst, Kyiv City, Odesa	4,600
	Film cassettes (119) - (used)	1999	Chernihiv, Kyiv Inst, Kyiv City, Odesa	23,800
	Film cassettes (15) - (used)	1999	Chernihiv, Kyiv Inst, Kyiv City, Odesa	1,175
	Clinical care supplies: otoscopes (3) & sphygmomanometers (3)	2000	Odesa	1,501
	Anti-nausea drugs for chemo study	1999	Odesa	5,700
	Mammography supplies & mammo film training sets	1998	seminar participants	4,345
	Mammography supplies, viewbox, mammo positioning textbook	2000	Chernihiv	2,649
	Mammography film cassettes and surgical supplies	2000	Chernihiv	3,054
	Mammography/radiology training manuals (77)	1998	seminar participants	9,120
	Mammography atlases (3)	1998	Kyiv Institute, Chernihiv, Odesa	420
	Radiology educational materials: videotapes & manuals	1998	seminar participants	565
	Surgery text books (4)	2000	Lviv Medical Univ.	535
	<b>Total Value</b>			<b>\$146,502</b>

**Attachment D**

**Materials Developed by Ukraine Breast Cancer Assistance Project  
and Distribution Chart**

## Materials Developed by Ukraine Breast Cancer Assistance Project

### For medical providers:

1. Clinical Breast Exam Curriculum (Russian)
2. Immunocytochemistry Manual (Russian)
3. Mammography Quality Control Manual (Russian)
4. Patient Positioning and Quality Control for the Mammography Technologists (Russian)
5. Fundamentals of Mammography: The Quest for the Quality. Positioning Guidebook (Russian)
6. Odesa Conference Abstracts, April 1999 (Russian)
7. Clinical Breast Exam Video (Ukrainian)
8. Psychosocial Training Manual for Breast Cancer (Ukrainian)
9. National Summation Conference Abstracts, November 1999 (Ukrainian)

### For women:

1. 11 Brochures
  - a. Lymphedema Booklet (Ukrainian)
  - b. Helping Yourself During Chemotherapy: 4 Steps for Patients (Ukrainian)
  - c. Health of the Woman (Ukrainian)
  - d. What You Need to Know about Breast Cancer (Russian)
  - e. Radiation Therapy and You: A Guide for Patients (Ukrainian)
  - f. Chemotherapy and You: A Guide to Self-Help During Treatment (Ukrainian)
  - g. Physical Exercises for Patients after Breast Cancer Surgery (Ukrainian)
  - h. Information About Mammography (Ukrainian)
  - i. Information About Clinical Breast Examination (Ukrainian)
  - j. Supporting Your Loved One Who Has Breast Cancer (Ukrainian)
  - k. Recovery is Achievable (Russian)
2. 4 Informational Flyers
  - a. Recommendations for Breast Self Exam (Ukrainian)
  - b. Eighteen Steps to Prevention of Lymphedema (Ukrainian)
  - c. Information About the Lymphatic System (Ukrainian)
  - d. Infectious Lymphangitis (Ukrainian)

3. 1 Poster  
Three Ways To Early Detection of Breast Cancer (Ukrainian)
4. 1 Shower Card  
Make Breast Self Exam Your Vitally Important Habit (Ukrainian)
5. Breast Self Exam Video (Ukrainian)
6. Relaxation Tape (Ukrainian and Russian)
7. TV Spots (3, Ukrainian)
8. Breast Cancer Peer Support Volunteer Training Curriculum (Ukrainian)

**Distribution of IEC Materials (1998-2000)**

IEC materials	MOH (Dr. Irkina)	Kyiv City Oncology Center	Foundation for Women's Health and Family Planning Association of Radiologists of Ukraine	Women's Consortium	Conferences/ Trainings	Kyiv City Health Center/ Kyiv Oblast Health Center	Odesa Oblast Oncology Center	Odesa Health Center	Chernihiv BC Support Group Victoria	Chernihiv Oblast Oncology Center/ Chernihiv Health Center	FAPs (Chernihiv Oblasts)	Others: Zhytomyr, Zaporizhzhia, Cherkasy, Kharkiv, Mykolayiv, Donetsk, L'viv	Institute of Oncology and Polyclinic	TOTAL Pieces
<b>POSTER</b>	350	60	120	150	60	350	1,000	150		2,500	100	100	60	5,000
<b>VIDEOS</b>	10	4	4		150		20	4	3	6			4	205
<b>FLYERS</b>														
Recommendations for BSE	3,000	1,350	6,000	2,500	1,050	1,500	4,500	1,500	1,000	5,000	200	1,700	1,000	27,800
Infectious Lymphangitis	3,000	2,050	1,000	200	600	1,000	3,550	1,000		4,500	200	1,400	1,500	20,000
18 Steps to Prevention of Lymphedema	2,500	2,050	600	1,300	700	1,000	4,000	500	250	4,500	200	1,700	2,000	20,000
Information about Lymphatic System	2,500	1,000	450	200	1,350	1,000	4,000	350	650	4,500	200	1,800	2,000	20,000
<b>BROCHURES</b>														
What You Need to Know about Breast Cancer	2,200	3,100	1,900	2,500	1,800	5,500	3,500	2,000	800	5,100	700	1,300	900	28,800
Radiation Therapy and You	710	1,400	1,040	300	2,100	2,200	3,150	100	100	4,450	700	2,300	1,000	19,550
Chemotherapy and You	780	1,760	500	300	1,940	1,700	3,000	100	100	5,400	700	1,700	720	18,700
Helping Yourself During Chemotherapy: 4 Steps for Patients	1,100	1,900	400	300	1,700	2,800	2,100	100	500	4,900	700	2,050	1,450	20,000
Physical Exercises for Patients after BC Surgery	1,000	2,000	800	700	1,420	2,700	2,300	1,700	500	3,600	700	1,800	780	20,000
Information about Mammography	1,500	2,550	3,900	500	2,000	1,500	2,500	1,300	500	8,000	550	800	2,500	25,600
Information about CBE	1,500	2,100	2,900	1,000	1,950	5,700	1,595	1,100	1,000	8,500	1,200	2,550	1,400	31,095
Lymphedema	900	3,450	400	200	1,600	2,150	3,000		200	5,200	200	1,950	750	18,050
Supporting Your Loved One Who Has BC	1,400	2,200	500	900	1,600	2,500	1,500	900	500	1,850	200	1,200	350	15,600
Health of the Woman	2,000	700	1,300	500	1,400	3,000	1,200	1,200		4,000	200	1,550	950	18,000
Recovery Is Achievable		400			300				400	400		300		1,800
<b>SHOWER CARDS</b>	400	420	400	350	600	1,000	700	700	250	830	300	650	400	7,000
<b>TOTAL</b>	<b>24,850</b>	<b>28,494</b>	<b>22,214</b>	<b>5,600</b>	<b>22,320</b>	<b>35,600</b>	<b>41,615</b>	<b>12,704</b>	<b>6,753</b>	<b>73,236</b>	<b>7,050</b>	<b>22,900</b>	<b>13,864</b>	<b>317,200</b>

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**Attachment E**  
**Regional Exchanges for Psychosocial Support**

## Regional Exchanges for Psychosocial Support

Over the course of the 1999-2000, numerous exchanges were organized between Ukrainian survivors (and medical providers) and their counterparts in Poland and Russia. The importance of these exchanges cannot be overstated. These opportunities to meet breast cancer survivors and professionals who are working towards similar goals in countries with similar political and economic backdrops has been essential in catalyzing Ukrainian women to action as they witnessed firsthand the range of possibilities that could be applied to their own efforts. The various exchanges are listed below:

- **October 1999:** Four health workers and five breast cancer survivors from Chernihiv and Kyiv, as well as two PATH Ukraine staff members, were hosted by breast cancer activists associated with the Polish National Coalition to Combat Breast Cancer and the Polish Federation of Amazonka Clubs. The Ukrainians participated in numerous "National Breast Cancer Awareness Month" activities taking place there, including a March for Life and Hope, which drew 2,000 participants. They also observed the use of a mobile mammography machine and met with National Coalition officers to discuss legislative and organizational issues.
- **November 1999:** The Executive Director of the National Coalition to Combat Breast Cancer, Maria Spasowska-Grochulska, and the head of the Polish Nurse's Association, Grażyna Kieźel, participated in the PATH-sponsored National Conference on Breast Cancer. Dr. Eugeny Demin, breast surgeon and founder of the survivor group, Nadezhda (Hope), in St. Petersburg, Russia, also participated. Following this conference, a three-hour seminar was convened with Ukrainian survivors from Chernihiv and Kyiv at which Ms. Spasowska-Grochulska, Ms. Kieźel, and Dr. Demin shared their experiences of establishing advocacy and peer support programs with survivors in their respective countries.
- **April 2000:** A total of 12 Ukrainians (three medical providers, one psychologist, two PATH staff members, and six survivors), representing Chernihiv, Kyiv, Lviv, and Zhytomyr, spent four days in St. Petersburg, Russia as guests of Dr. Demin's group, Nadezhda, an official chapter of the international group, Reach to Recovery. The Ukrainians participated in a two-day conference sponsored by Nadezhda and had numerous opportunities to exchange information about their respective efforts to provide psychosocial support and information to newly diagnosed women, as well as survivors.
- **May 2000:** Ms. Spasowska-Grochulska, Ms. Kieźel, and a rehabilitation doctor from Warsaw's oncology hospital returned to Ukraine to participate in the PATH-sponsored national symposium for breast cancer survivors in Kyiv. Also in attendance were Dr. Demin and two survivors from St. Petersburg.
- **September 2000:** Five survivors, representing Chernihiv, Kyiv, and Zhytomyr, traveled to Poland as guests of the Federation of Amazonka Clubs for a two-week retreat. Activities included training sessions in fundraising, support group facilitation, lymphedema prevention, relaxation methods, and political advocacy.

Another group of survivors returned to Poland in October 2000, with separate funding. Finally, Ukrainian survivors are invited to participate in a regional conference for breast cancer survivors that will be convened in Warsaw in September 2001.

**Attachment F**

**Position Paper #1: Clinical Breast Examination  
as the Primary Breast Cancer Screening Tool  
for Ukraine (2000-2005)**

# Clinical Breast Examination as the Primary Breast Cancer Screening Tool for Ukraine (2000-2005)

## PATH Position Paper

September 2000

### Background

*Epidemiology.* Breast cancer is the leading cause of cancer death among women in Ukraine. In 1998 (the latest available figures) there were 14,615 new cases and more than 8,000 deaths nationally, an increase in incidence of 6.4% in the 7 years since 1992. The crude incidence rate (per 100,000 women) was 54.3, while the age-standardized rate was 36.6. This compares with a crude rate of 115.4 and an age-standardized rate of 94.6 in the United States in 1997 (SEER Cancer Statistics Review, 1973-1997). The rate varies widely within Ukraine (see Figure 1, attached), even when considering the different age distributions, from a low age-standardized rate of 27.2 in Zakarpattia oblast in 1998 to a high age-standardized rate of 53.3 in Odesa oblast. Incidence rates are highest among women aged 60-64 (137.9/100,000), but they first climb above 100/100,000 among women aged 45-49 and remain elevated through age 79 (see Figure 2, attached, with examples from several high- and low-incidence regions). More than 70% of cases in Ukraine occur among women 50 years old or more, with another 20% among women 40-49. Only 2% of cases occur among women younger than 35 years.

It is well known that early detection of breast cancer has a big impact on treatment and survival for women ages 50 and above. About one-third of new cases in Ukraine are identified only in the late stages (III and IV), when regional or distant spread has already occurred and treatment is less effective (compared with about 9% of new cases in the United States). Only about 12% of new cases in 1998 were identified in Stage I, when treatment is most successful and least traumatic (compared with about 40% in the United States).

*Current breast cancer screening and diagnostic practices in Ukraine.* Of the three possible methods for screening for breast cancer, only clinical breast examination (CBE) has been routinely promoted in Ukraine. Although CBE is supposed to be a regular part of women's health care, there are no data on how many women actually receive CBE annually nor on the results of such examinations. Both doctors and nurses report that they receive no special training on how to conduct proper CBE. However, in selected areas, more than 1000 health workers have recently been trained using the new curriculum developed by PATH. With the economic difficulties of recent years, the number of women seeking preventive care (or any care) has reportedly declined, so the opportunities for CBE are decreasing. Even when CBE is done and an abnormal result is found, women are often unable or unwilling to get further diagnostic evaluation and appropriate treatment.

Monthly breast self-examination (BSE), another possible technique for finding cancer earlier, is not widely known or practiced in Ukraine. Health workers have not been trained in methods for teaching BSE to women. As a result of special projects, there are now materials available for explaining and promoting BSE, although the quantity is limited.

Screening mammography is carried out on a very small scale in Ukraine, primarily because of very limited mammography equipment and supplies. A recent review by the Ukrainian Association of Radiologists (1998) found that in the 17 oblasts surveyed (which did not include Kyiv, Kharkiv or Sebastopol) there were only 134 functioning mammography machines. Less than 10% of these were modern machines (although a few new machines have been added since that time). The report also concluded that few radiologists have good skills in reading *screening* mammograms, due to the lack of specialized training or sufficient experience. Similarly, few radiologic technologists have received specialized training in mammography, although a new three-day curriculum is now available (along with a handful of trainers).

Mammography has several important roles in the *diagnostic* process also, along with ultrasound. Most mammography is currently performed for women with suspicious lumps identified by doctors or the women themselves. However, its use for guiding biopsy (wire localization) or for checking post-biopsy is quite limited. Ultrasound is more widely available, but not always with the correct probe. A few specialists have received training in ultrasound-guided needle biopsy, but the supply of appropriate needles is inadequate.

While some fine needle aspiration biopsies are done, most biopsies consist of frozen sections performed on surgically obtained specimens. Pathology supplies and equipment for histologic analysis are in short supply or poor condition at many cancer hospitals. Tests for hormone receptors and pathologists trained to use them exist at only a few centers such as Kyiv, Lviv, and Chernihiv.

*Practices in other countries.* In 22 industrialized countries surveyed in 1995 (where rates of breast cancer tend to be higher than in Ukraine), screening by mammography was the standard (three also use CBE, and four add CBE and BSE). The eligible age groups and screening intervals varied, as did the rates of coverage achieved. Countries with lower breast cancer rates and/or limited health care resources do not generally attempt screening mammography programs.

### Proposed Approach

Given the current Ukrainian breast cancer epidemiology and resources, the strategy proposed to begin advances in screening for this country relies on **annual clinical breast exam** for all women aged 35 and older by trained medical workers (preferably female). This should be done by midwives, feldshers, and gynecologists at health facilities right in the communities where women live. Training for those responsible for screening should include basic information on the biology and current survival rates, the range of breast findings that might be related to an abnormal CBE, and the treatment options women might face. This will enable them to properly inform women and to reduce unwarranted anxiety. All other medical workers should take an active role in asking women whether they have been screened by clinical breast examination that year and encouraging them to do so if they have not been. **Monthly breast self-examination** should be promoted as a way of increasing public awareness of the importance of early detection and increasing individual acceptance of a woman's role to protect her own health by both BSE and CBE. There are no good studies showing a decrease in mortality due to regular BSE, but it may be helpful as an educational tool. A system for tracking coverage of the eligible population

with CBE and for assuring that those with abnormal exams receive diagnostic evaluation and treatment, if needed, should be established.

Existing mammography units and any new capacity should be focused on **diagnostic imaging** needs (rather than screening) until the infrastructure and resources are in place so that all women with abnormal CBEs can be adequately evaluated. Each oncodispenser or metropolitan diagnostic center should have at least one modern mammography machine and ultrasound with MHz7.5 probe. The use of ultrasound to rule out cysts will reduce the number of biopsies needed, and its use to guide fine needle aspiration or core needle biopsies will improve their quality. **National guidelines for pathology services** related to breast cancer should be reviewed and/or instituted. Hormone receptor testing should become a routine part of the pathologic analysis as soon as possible, since the information will greatly aid in the choice of therapies.

Once CBE is widely and effectively practiced and surplus mammographic capacity exists (that is, after all women with abnormal CBEs are receiving appropriate diagnostic evaluation), then a screening mammography program targeted at women 45-69 years old could be *added* to the CBE program. Special priority for mammographic screening should be given to the three areas with the highest incidence rates, according to 1999 Cancer Registry data (the cities of Sebastopol and Kyiv and Odesa oblast), where screening mammography will be most cost-effective.

#### Rationale for CBE-based Approach

There are several important reasons why Ukraine should consider an approach based on CBE rather than mammography at the present time. These relate primarily to the cost-effectiveness of different strategies, which depends in turn on the local epidemiology, the performance of various screening tests, existing infrastructure and resources, and the capital and recurrent costs associated with different approaches. Given the variability within the country, those oblasts or cities with the highest incidence rates or with greater financial resources might be ready to add a mammography-based component sooner than the rest of the country.

- **Clinical breast exam (CBE) is moderately sensitive and highly specific.** The sensitivity of CBE is dependent on the skill of the medical worker, the size and density of the breast, and the size of prevalent tumors. One meta-analysis (Barton et al, 1999) found the sensitivity of CBE to be 54% and the specificity 94%. Studies in Canada (Baines et al, 1989), Japan (Morimoto et al, 1997; Ohuchi et al, 1995; Kanemura et al, 1999) and the U.S. (Bobo et al, 2000) have reported CBE sensitivity levels of about 50-85%, with higher rates for women in their 40s and declining somewhat for older women. Specificity was somewhat higher for women 50 and older. Since there has been little screening in recent years, there is a higher rate of larger tumors prevalent in the population of Ukraine. Such tumors can be as easily detected by CBE as by mammography. CBE can also detect many small tumors, when done properly. In the U.S. study (Barton et al, 1999), based on 752,081 CBEs from 1995-98, 25% of the cancers identified were *in situ*.
- **Mammography detects 31-64% more cancer cases than CBE, but at a cost 500-800% higher.** The ability of mammography to detect cancer depends on many factors: quality of equipment and film, skill of technologist and radiologist, breast density (Mandelson et al,

2000), and size of prevalent tumors. A recent meta-analysis of mammography (based on studies from Sweden, Canada, Netherlands, and USA) found that sensitivity ranged from 83% to 95%, and specificity from 93.5% to 99.1% (Mushlin et al, 1998). Based on the three studies that included women 40-49, it appears that sensitivity for women in their 40s is about 10 percentage points lower than for women 50-59 (Mushlin et al, 1998). Most units in Ukraine would not have such good conditions at present and should expect somewhat lower sensitivity. In addition, breast density in Ukraine tends to be greater, further reducing expected sensitivity.

**Table 1. Screening Cost per Breast Cancer Case Detected**

Screening model	Incidence Level/100,000		
	70	100	150
CBE (55%)/MM \$5	\$19.92	\$13.96	\$9.32
CBE (65%)/MM \$5	\$16.87	\$11.82	\$7.90
MM \$5	\$92.44	\$64.71	\$43.14
CBE (55%)/MM \$8	\$23.93	\$16.77	\$11.21
MM \$8	\$147.90	\$103.53	\$69.02

Table 1 shows sample costs based on assumptions of CBE costs of \$0.50 (labor) followed by mammography for those with abnormal exams, with mammography costs estimated at two different levels (\$5 and \$8). This only counts the recurrent costs (labor, supplies) of mammography. It assumes CBE sensitivity levels of 55% and 65% and MM sensitivity of 85% (and 98% after abnormal CBE). It assumes 5% of CBEs will be abnormal and 10% of screening MMs will need additional mammography.

- **The screening cost per cancer case detected is higher when incidence is lower.** Using Table 1 again, we see the cost per case detected for 3 levels of incidence (typical of different oblasts and age groups in Ukraine). While the cost per case detected increases for both mammography (MM) and clinical breast exam (CBE) as incidence declines, the premium (added cost) for MM over CBE increases much more (\$73 extra versus \$34 extra) at low incidence.
- **The incidence rate among women under 35 is too low to justify active screening.** Incidence rates among women 30-34 ranged from 0 to 20.9 per 100,000 in 1999. Even with CBE's high specificity (95%), approximately 5000 women would have abnormal CBEs and the associated diagnostic evaluations to find 6-12 expected cancers. The cost to the health care system and the cost, distress and trauma for the healthy women is unwarranted.
- **Mammography has much higher capital (as well as recurrent) costs than CBE.** One mammography machine (which can screen about 6,000 women per year if fully utilized) costs about \$50,000-\$80,000. An additional \$10,000-\$15,000 is needed for a film processor and accessory equipment. The initial MM training for radiologists and technologists is far more expensive than that for CBE, although fewer people would have to be trained. Ukraine has nearly 8 million women aged 45-69 (about 16% of the total population), which would

require 1320 mammography units, plus about 10% more for diagnostic evaluation (1450 minus the 50 or so already available). At \$60,000 each, the 1400 units needed (in addition to existing modern machines) would cost approximately \$84 million. If refurbished units were purchased at \$20,000-\$30,000 each, the cost could be reduced to \$28-\$42 million.

- **CBE is better suited to rural populations and small towns than MM.** MM requires concentrated numbers to assure efficient utilization of the equipment and to enable radiologists to maintain their interpretive skills. When transport is difficult (as it is now in Ukraine), only CBE can be brought to locations convenient to rural and town populations.
- **Most of the resources to get started with CBE already exist.** Ukraine has an excellent system of health facilities at the community level (FAPs and polyclinics) and good referral links. These facilities are staffed by people who can learn effective CBE and who would be acceptable to women. The policy and tradition of CBE is well established. A new 1-day CBE curriculum and several master trainers for CBE are available to give refresher training to midwives, feldshers, gynecologists, and oncologists. Funds are needed to reproduce training materials, and the health information system needs some modifications to enable proper monitoring of the early detection program.
- **Mammography capacity is very limited; priority should be given to diagnostic use.** Those women with an abnormal CBE must be assured of getting an effective diagnostic evaluation, with high quality mammography, ultrasound and biopsy. They should have get priority (over screening clients) as long as mammography capacity is inadequate.

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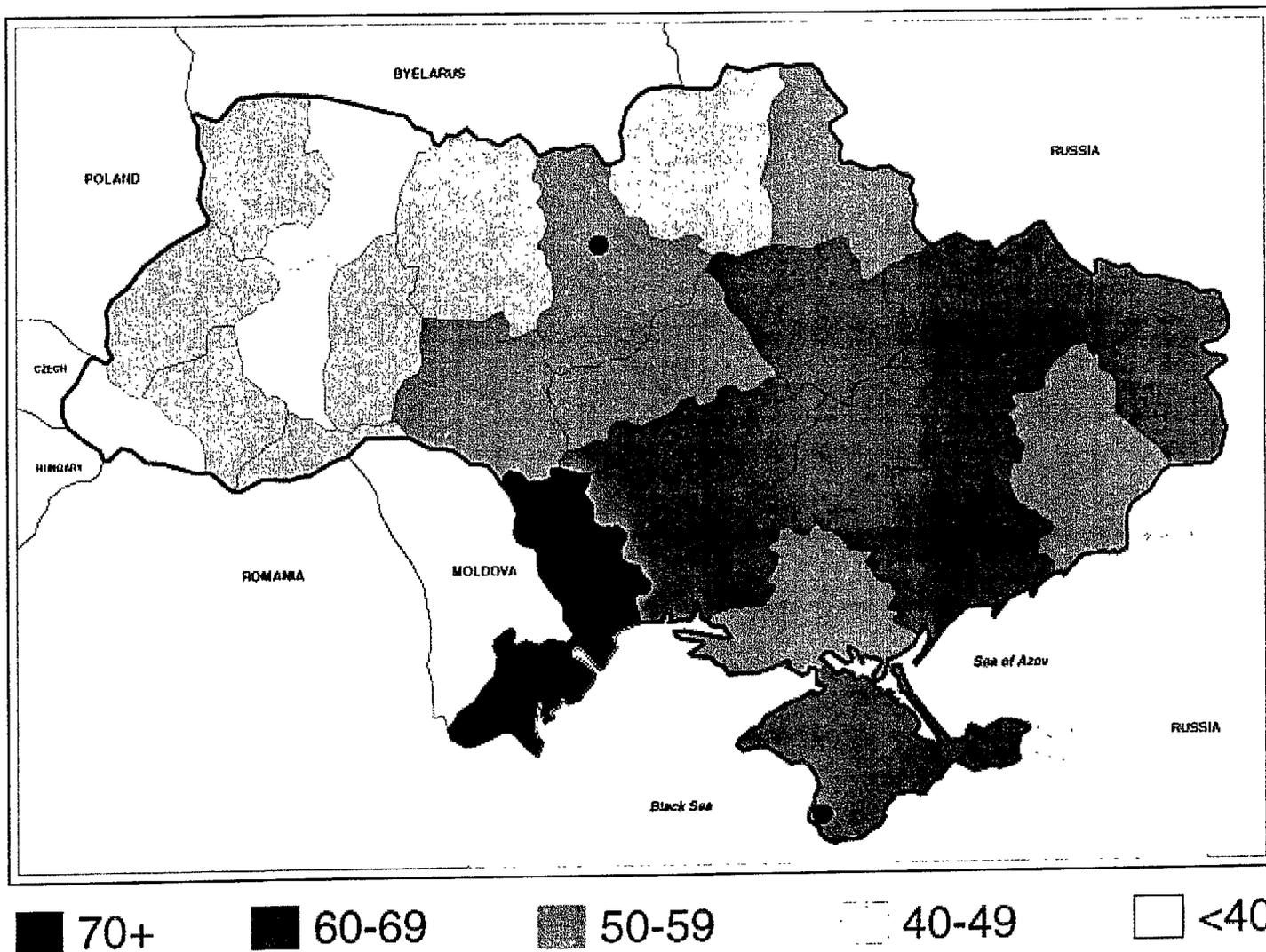
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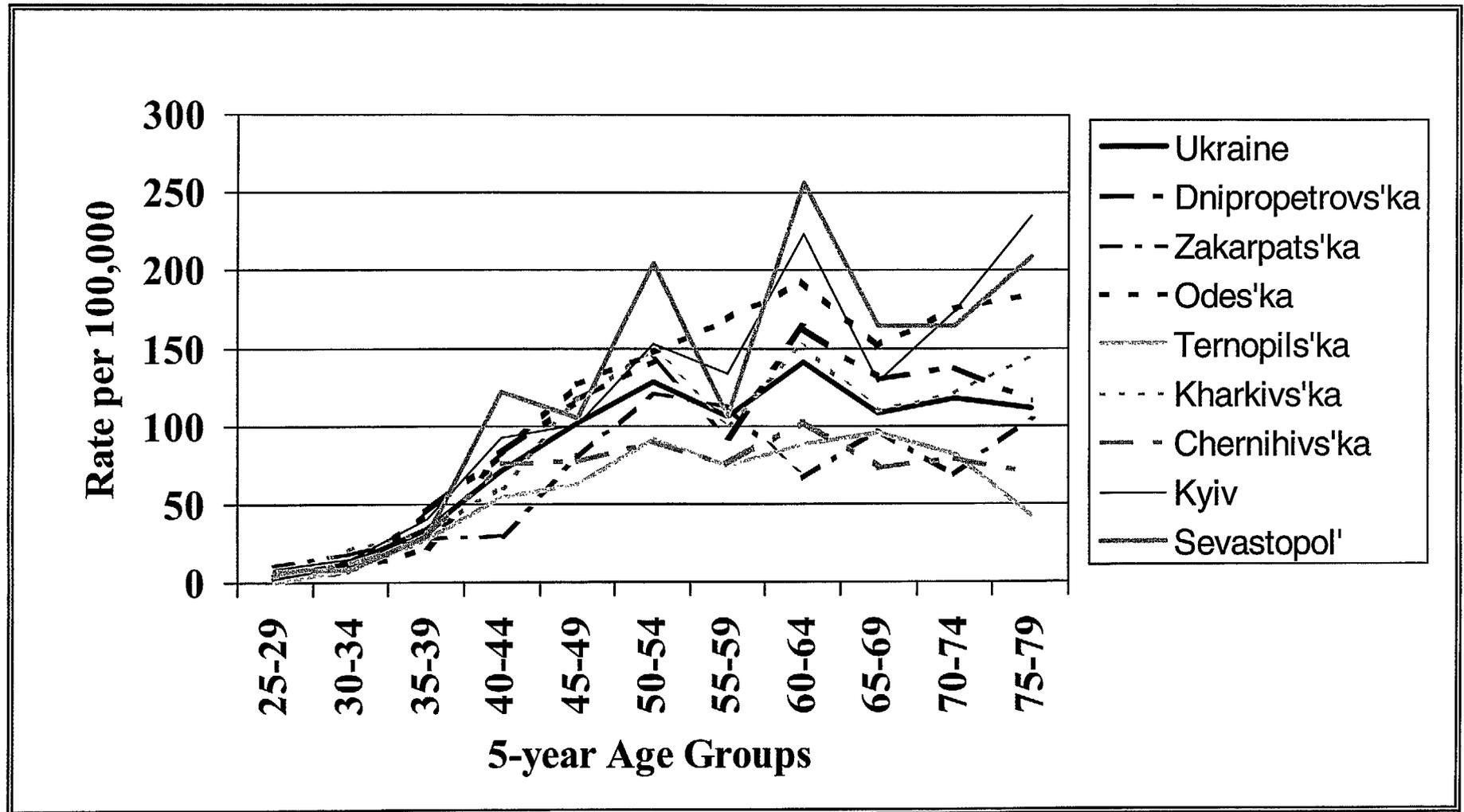
# Захворюваність на рак молочної залози, Україна, 1999



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# Figure 2: Age-specific Breast Cancer Incidence

## Ukraine and Selected Regions, 1999



**Attachment G**

**Early Detection of Breast Cancer in Ukraine  
Strategies and Lessons Learned for Future Planning**

# Early Detection of Breast Cancer in Ukraine

*Strategies and Lessons Learned for Future Planning*

*PATH Workshop, September 13-15, 2000*

Report



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### Attachments

Attachment A: Agenda and List of Participants

Attachment B: Proposed Breast Cancer Early Detection Strategy for Ukraine (2000-2005),  
PATH Position Paper, September 2000

## Introduction

This meeting was convened by PATH as part of its Ukraine Breast Cancer Assistance Project, supported by United States Agency for International Development (USAID). It brought together 30 Ukrainian professionals representing different medical specialties from 9 oblasts (see Attachment A for the meeting agenda and list of participants). The purposes of the meeting were to:

- identify key elements of an early detection strategy for breast cancer,
- survey current experience in Ukraine and lessons learned so far,
- assess available resources,
- consider the early detection strategy proposed by PATH,
- begin group planning and problem-solving,
- identify areas of consensus, and
- develop recommendations and identify the next steps that are needed.

This was the final meeting of the project and was designed to bring together those individuals with experience and responsibility for early detection of breast cancer. The PATH-supported-early detection, pilot program in Chernihiv Oblast had enabled local participants to gain experience with many important issues, but several other oblasts and cities had also initiated screening programs in the three years since the project started and had valuable expertise to share. Dr. Antonenkova, representative from the main department of Women's and Children's Health in the Ministry of Health (MOH), opened the program by noting that many women are lost to breast cancer because they seek care too late, and that the hands and hearts of these women are needed by their families, communities, and country. She cautioned that one recipe will not work for all countries and that the participants should strive to find a strategy that was suited to Ukraine, based on their various experiences in different oblasts.

Dr. Radziewska of USAID explained that one purpose of her agency was to provide opportunities for Ukrainian and American colleagues to have open discussion. She encouraged participants to analyze their various experiences, apply them to finding ways to do early detection with limited resources, to develop recommendations for the MOH, and to disseminate their ideas to others.

Dr. Gamazina of PATH Ukraine gave a brief introduction to PATH, an international nongovernmental organization, and its six years of work in Ukraine. She described the various aspects of the Breast Cancer Assistance Project, including training and symposia on clinical issues such as chemotherapy, surgery, pathology, radiology; provision of equipment and supplies; the pilot early detection program in Chernihiv; and psychosocial training for medical workers as well as assistance to new breast cancer survivor support groups. She briefly reviewed the agenda for the meeting and called on everyone to participate actively.

## Key Components of an Early Detection Program

Dr. Tsu of PATH Seattle reviewed the basic elements of an early detection program. First, early detection was defined as screening of asymptomatic women, appropriate diagnosis, and referral for treatment. If any one of these aspects is weak, early detection will be compromised. In order to put an effective early detection program together, the following eight elements must be addressed.

1. *Detection methods.* For screening, the options include clinical breast examination (CBE), mammography, and breast self-examination (BSE). Which of these methods a program uses will depend on local disease prevalence rates, the level of efficacy expected, available funding, and the existing infrastructure. The detection methods required for diagnosis include mammography, ultrasound, and various types of biopsy. Most countries in Europe and North America rely on mammography for screening, while seven countries combine mammography with CBE.
2. *Target groups.* The groups that programs try to reach are defined primarily by upper and lower age limits. The actual cutoff points should be determined by local disease patterns and life expectancy and by which detection method is being used (e.g., mammography is generally more effective among older women). Most European countries set a lower limit for mammography at age 50 and an upper limit at age 65 or 70. Sometimes special risk factors like family history of early breast or uterine cancer, late first pregnancy, or never having been screened, or geographic areas with significantly higher disease rates might also influence the choice of priority target groups.
3. *Screening intervals.* Most experts recommend annual intervals for CBE and monthly intervals for BSE. For screening mammography most countries recommend one- or two-year intervals, sometimes depending on the age of the woman.
4. *Organization of services.* Several aspects need to be considered here, including: the degree of centralization of programs; whether they will be managed by primary health care or oncology services; what mix of specialist facilities, general facilities, and mobile services to use; whether to employ passive systems or active outreach; whether to organize around a particular facility or a defined population; and how the referral system is organized.
5. *Public awareness.* It is critical to get women to seek screening services and to follow up on any referrals for further evaluation or care. To build public awareness and understanding of early detection, key messages to communicate must first be defined. These should include information on the value of early detection, who needs to take action, and what practical steps they must take. Appropriate mass media for the region must be selected, and effective interpersonal channels should also be identified. A coordinated campaign combining these elements will be most effective. (Print materials and short radio and television spots produced by PATH were mentioned as available resources.)

6. *Provider training and awareness.* Several groups of medical workers will need refresher training, such as gynecologists, feldshers, midwives, surgeons, radiologists, and pathologists. In addition, all medical workers should be oriented to their responsibility to use all appropriate opportunities to screen women or to actively recommend and refer women to screening. (The curricula on CBE, mammography positioning, and psychosocial support developed by PATH were mentioned as available resources.)
7. *Financing.* This is a major concern for all programs. Participants were asked to consider how necessary supplies, training, and mass media could be financed.
8. *Monitoring and evaluation.* This is critical for managing programs (both quality and use of resources) and for generating or maintaining political support for them. Since it is difficult to measure the ultimate outcome of reduced mortality, three intermediate indicators of success were suggested: coverage, quality of care, and cost-effectiveness. Specific indicators for effectiveness and efficiency were suggested for facilities and for raions and oblasts.

These eight components were addressed in the descriptions of local programs, and several were to be considered in the subsequent small group sessions of the meeting.

## **Current Experience and Lessons Learned**

### ***Chernihiv Oblast***

Dr. Zotov, Chief Doctor of the Chernihiv Oblast Oncology Hospital, described the pilot program they had developed in collaboration with PATH. It is based on the use of CBE throughout the oblast, education about BSE through public campaigns and individual patient contacts, and screening mammography in a limited area. They have trained specialists in several disciplines, and have provided training on psychosocial support to patients, and have developed a survivors' support and volunteer outreach group. They organized a council of representatives from different offices to serve as a coordinating group within the oblast. They had an extensive public awareness campaign, running short spots on television every two weeks, developing a 30-minute film for television, running local spots on BSE, participating in roundtable discussions on television, and generally working closely with television journalists to enlist their support and understanding. They were also active in getting articles into the newspapers and magazines, again building relationships with local journalists so they could ensure the accuracy of the material printed, and in shaping the messages that went out. They cooperated closely with the oblast Health Education Center that helped in distributing materials and publishing the articles in newspapers. They distributed the posters, shower cards on BSE, and more than 20,000 brochures which they had helped develop with the PATH project.

Their mammography-screening program is based in a special center in the oncology hospital and offers free screening mammography to women aged 45 to 69. They use a single film for each breast and encourage women to return in two years. Their radiologists and technologists attended special training seminars to upgrade their mammography skills. They maintain a careful quality control program for their equipment and have organized a computerized database for tracking

their mammography patients. They found that urban women and younger women were more likely to come for mammography than rural or older women.

With regard to CBE, nine doctors and six midwives were trained as master trainers through the PATH project. They organized a special training room in the hospital where more than 300 doctors and more than 200 other medical workers have now been trained in CBE. They have also worked with the local medical training institutions to incorporate the CBE module in the regular curriculum for oblast postgraduate training of feldshers, nurses, and midwives.

In the area of financing, Dr. Zotov reported that screening mammography is very expensive. He had calculated that for the 150,000 women aged 45 to 69 in the oblast to be screened by mammography once every two years (assuming that one unit can serve about 5,000 women each year) would require 15 mammography units, just for screening. He estimated the cost of screening mammography (films, chemicals, and equipment maintenance, but not salaries) at Hrv.80 per woman. Since funding is so limited, he suggested that CBE must be used widely to select women needing mammographic evaluation. Of the 18,000 women screened by CBE in Chernihiv raion, a little more than 200 were referred for mammography. They hope to be able to continue to find the Hrv. 40,000 to Hrv. 50,000 per year needed, either from their local city council or from local sponsors. Perhaps they will eventually be able to ask women to pay at least part of the cost, but that is not allowed now. They had tried posting a notice requesting voluntary donations from patients but had been told by a lawyer that it might be considered "coercive" and therefore against the law.

In the area of evaluation and monitoring, Dr. Zotov mentioned the need for adjusting the data system to pick up essential information. This is not difficult to do technically, but depends on the availability of modern computer equipment to process the appropriate information. This system was able to help them track the women who did not come in for the recommended follow-up.

In response to questions afterwards, Dr. Zotov said that clinicians already had enough time to do proper CBE and did not need extra time to be allotted. With regard to the number of cases before and since the screening program started, he said that the number of cases had risen a little but it was still too early to see a big change; he also mentioned that they had found a lot of benign breast disease. The suggestion was made that CBE be done on all female in-patients at the hospital; Order No. 208 already requires this, but the overall impact is rather small.

### ***Lviv Railway Hospital***

Dr. Gutsal, Chief of Women's Health for the hospital, described the activities of their Women's Wellness Center, developed in collaboration with AIHA. They have provided education for staff, have worked with local mass media, and are working with the local survivors' group. They are a multidisciplinary center with two gynecologists, one radiologist, and one psychologist. They offer mammography, ultrasound and fine needle aspiration, and core needle biopsy; they do breast surgery in the Railway Hospital but refer women to the oncology hospital for radiotherapy and chemotherapy. They require their own female staff to be screened annually before being permitted to take vacation. In the 1998 to 2000 period, they screened 1,388 women. They have offered refresher training on various aspects of breast care, CBE, and how to teach women BSE.

They hope to become the chief breast health center for the railway health system in the future. Their services are financed through sponsors and an "insurance" system.

In the questions afterward, there was a lively discussion about the "insurance" system. The insurance company acts as an intermediary between the hospital and the patients. Patients pay Hrv. 70 to the insurance company, and the company pays the center. It costs the hospital Hrv. 60 to 70 to buy four films for a two-view mammography (and associated costs).

Dr. Kens, surgeon-oncologist of the Railway Hospital, said that a combination of methods was very important both for screening and for diagnosis. They had found it very useful to bring all the methods (mammography, ultrasound, and cytology) together in one unit. When asked if ultrasound should be used to screen first, Dr. Kens replied that ultrasound could be used first if there was a palpable mass. Dr. Gutsal said their policy was to use ultrasound first if the woman were younger than 37 to see if the mass was a cyst or a solid mass, but to use mammography first if the woman were 37 years or older.

### ***Odesa Oblast General Hospital***

Dr. Voityshyn, Chief of the Admissions Department, described the program of the Women's Wellness Center, developed in collaboration with AIHA. They provide mammography screening to their staff and to those from the area near the hospital who come in requesting screening. They provide diagnostic services to those who come in with symptoms and refer most cancer cases to the oblast oncology hospital. They manage benign breast problems in their own hospital. In 1999 they provided screening mammography for 243 women from the hospital staff and found 5 small cancers. Most of their mammography (e.g., more than 4,000 women in 1999 but less than half of that in 2000) is diagnostic, as is all their ultrasound.

They organize seminars and training for other medical workers in the oblast and distribute print materials on BSE to women who come into their center. They put some messages on television and in the local newspaper but found that too many women wanted to come and they were overwhelmed. They recommend BSE for all women 20 years and older, annual CBE for all women 40 and older; and mammography every two years for women 40 to 49 and annually for women 50 and older. However, given the limited resources they now think they will have to focus on CBE as their primary screening method. They have very little financing since the AIHA project is ending, so they are looking for sponsors. They are hoping that during the upcoming Year of Health declared by the President, local mayors and enterprises may be more willing to support their work. They estimate that they need US\$50,000 to US\$80,000 per year.

In the questions afterwards, one person asked why they found it difficult to do only about 3,000 mammograms per year since this was less than 12 each day. Dr. Voityshyn replied that they knew what was needed but did not have the necessary funding. Women currently pay Hrv.40 to Hrv.50 for the service, and they have a fund to support those who cannot pay.

### ***Kyiv Hospital Number 3, Left Bank***

Dr. Yatsuk, Chief of the Radiological Department, described their Women's Wellness Center, established in 1999 in collaboration with AIHA. Mammography is their principal screening method, but they have a multidisciplinary team in their center to do education, screening, and diagnosis. They refer cancer patients to Kyiv City Oncology Center and the National Institute of Oncology for treatment. They offer mammography, ultrasound, cytology, and histology services, as well as classes for women on various aspects of women's health.

In the first year and a half, they have provided screening mammography for about 1,250 women 40 years and older and diagnostic mammography for about 350 additional women. Dr. Yatsuk acknowledged that they cannot serve all the women in their area with just one machine.

In response to a question about follow-up for referred patients, Dr. Yatsuk said that, although they do not have a raion oncologist, they have assigned a doctor who does this checking. She also confirmed that they take quality control very seriously; for example, they made an air-conditioned room for the film processing equipment.

### ***Donetsk Oblast Diagnostic Center***

Dr. Bilonenko, Chief of the Mammological Center of Donetsk Oblast Diagnostic Center and President of *Agatha* Association, described the situation in Donetsk and the work of *Agatha*. Most cancer cases are still identified by palpation, followed by surgical biopsy. Fewer than 2,000 women receive mammograms each year (out of a total population of 2.5 million). They have 15 mammography machines, but only two are of modern design. As a result, they rely heavily on ultrasound. They find many surgical biopsies are negative and attribute this to poor quality of CBE, inadequate use of mammography and ultrasound, and poor training of specialists. Referral links to ensure that women with detected masses get adequate diagnosis and treatment are poorly organized except in one or two cities. They have sponsored annual seminars for different types of medical workers and have published several articles. They have prepared recommendations on ultrasound and on treatment for their oblast, but they believe special breast health centers and better coordination are needed.

*Agatha* was established as a center for selective screening of high-risk women, defined as those with a family history of breast cancer or those with hyperplasia or hyperestrogenemia. Dr. Bilonenko recommended that local polyclinics should have special breast health rooms and that the focus should be on high-risk women.

### ***Kherson Oblast***

Dr. Miakinkov, Chief of the Radiological Department of the Kherson Oblast Oncology Hospital, described the situation in Kherson. They started doing mammography screening about five years ago (about 3,000 women each year), but after a few years their specialist left and the numbers declined a little. All patients have CBE first. They do not have enough capacity to provide mammography to all women over 50 years, as they would like, so they focus on high-risk

women with family cancer history or menstrual problems. In the early years of activity, they saw an increase in the number of cancer cases identified, but more of them were in the early stages. He noted that the referral link between the diagnostic center and the oncology hospital was working well, but that radiologists were not well connected to other medical specialties.

### ***Chernivtsi Oblast***

Dr. Kryvchansky, Chief of the Mammology Center of the oblast oncology hospital, described current activities in his oblast. In the past three years, the oncology hospital has done only 1,500 mammograms, of which about half were for screening. They charged Hrv. 8 for local Swema x-ray film (not mammography grade). Recently, a group of business people purchased a modern mammography unit and set up a private clinic which offers screening from 9:00 in the morning to 7:00 in the evening for Hrv. 37 (which includes four Kodak films). In less than two years, they have screened about 1,500 women. It takes them about 15 to 18 minutes for each patient, so they can serve 40 to 50 women each day. They also offer cytology and biopsy.

### ***Sevastopol'***

Dr. Serdukova, radiologist of the city oncology hospital, described some of the challenges they are facing. They have only a very old Elektronika mammography machine; they had four, but have used them for parts to keep one functioning. They do primarily diagnostic mammography and serve about 1,200 women each year (out of a female population of about 187,000). There is no active or organized screening program, despite the fact that breast cancer incidence seems to be rising steadily.

## **Detection and Diagnosis Methods**

This session provided information on the experience and resources in Ukraine related to clinical breast exam, breast imaging, and pathology related to breast cancer. In addition, representatives from the Cancer Registry provided a brief review of current data on breast cancer from their sources.

### ***Clinical Breast Exam***

*Training strategies and resources.* Dr. Khokhlich, Professor at Kyiv Nursing School #3, described the CBE training activities which she has been conducting. Doctors, nurses, and feldshers are all good candidates for CBE training. In pre-service training (e.g., nursing school) she experienced good results, as learners are eager and enthusiastic. She has found that in-service training among established professionals is a little more difficult, as people are more resistant to changing their practices and ideas. The third key group to receive this training was the professors at nursing and medical schools, who have been given copies of the curriculum developed by PATH. She explained that CBE training was needed because very few health workers knew how to do CBE correctly. It was not really taught either initially or in later postgraduate courses; for example, surgeons receive only two hours of course work on all aspects of the breast in some schools. The curriculum includes a slide-lecture on anatomy and problems of breast cancer in Ukraine, videos on CBE and BSE, use of synthetic breast models with several lumps in them,

use of patients as models whenever possible, and supportive print materials. This curriculum has now been incorporated into the State unified curriculum for all nursing schools, and materials from it were included in Dr. Khokhlich's recent book on practical gynecology. She noted that the curriculum must still be incorporated into the medical school courses and into postgraduate courses for doctors, feldshers, and midwives.

*Monitoring for coverage and effectiveness.* Dr. Gamazina of PATH Ukraine spoke on behalf of Chernihiv raion about the changes they had made in their health information system to enable them to track CBE coverage. They added just one variable to their computerized record on outpatient visits to FAPs and clinics, with assistance from the oblast statistical bureau. The variable asked about CBE and offered three options: normal, abnormal, and not done. With just this information in the database, they were able to calculate overall, age-specific, and facility-specific rates of CBE coverage; overall, age-specific, and facility-specific rates of abnormal exams; and lists of those needing follow-up referral for evaluation or treatment. Chernihiv raion data for 1999 to 2000 showed that coverage for CBE was quite high (89% overall in 1999), but coverage among women 65 years and older is lagging behind other groups a little (87% vs. 93% among women 45 to 49). The data suggest that two districts in the raion may have personnel needing remedial training, since their detection rates (at 0% and 0.1%) were much lower than the average rate of abnormal (1.2%). Comparing 1999 with the first half of 2000, coverage had gone up in all groups except those 65 and older, where it had actually dropped slightly. This information, which is easily generated by the database but which could also be collected by paper reports, provides very useful information to raion officials responsible for managing an early detection program. The list of patients needing referral was shared with the mammography unit to see who had actually come in for evaluation and their outcomes.

In the discussion afterwards a question was raised about how to identify abnormal CBE findings and the referral process. In general, midwives and feldshers cannot distinguish different types of masses or thickening of tissue; they should just consider those patients abnormal and refer them to the raion oncologist for further evaluation before they go to the oncology hospital.

*Mobilizing health workers.* Dr. Zotov spoke about several mechanisms for raising awareness of CBE among health workers. Of course, the various special training courses, the routine post-graduate courses for doctors, and the training courses for paramedical personnel held routinely at the oblast general hospital will all help to heighten awareness about the need to do CBE. In addition to teaching them how to do it, though, they need to be convinced as to the importance and value of doing it (or of recommending it to women, even if they are not the right person to do the exam).

## **Breast Imaging**

*Mammography: current resources and prospects for the future.* Professor Babiy, President of the Ukrainian Association of Radiologists (UAR), reported on the status of modern mammography in Ukraine. There are about 315 mammography units in the country, of which only 15 to 20 are of modern design. He noted the low numbers of mammograms done in Ukraine (less than 100,000 in 1999), as compared to about one million in Britain, which has a similar population size. The average number of mammograms done each year for each reported machine is also

quite low, varying from about 1,000/machine in Kyiv to fewer than 30/machine in Poltava. This low utilization raises questions of whether the reported machines are all functional and whether there is a need to redistribute underutilized machines to oblasts without equipment. He remarked that there is clearly no organized mammography-screening program in the country serving a substantial proportion of the population. He commented on the lack of any official training in mammography for radiologists and said the UAR would ask departments at the medical universities to develop subspecialty training in this area. For the future, they would like to organize a national or regional training center where mammography specialists could be trained and certified.

In the discussion afterwards, people from several oblasts commented that although there were officially mammography units in their oblast many, if not most, were 20 years old or more and were not working. They also noted that where raions had such equipment, the technique and quality were very poor and women were often forced to repeat films several times. The question of mobile services was raised, but Dr. Gutsal from Lviv reported that they had tried putting a mammography unit in a railway car to do mobile services and found it to be quite complicated and not very successful.

*Ultrasound: current resources and future prospects.* Dr. Bilonenko of Donetsk reported that ultrasound units are much more widely available than mammography machines and less expensive to use. Ultrasound has a valuable role to play in evaluating a palpable mass. He noted that ultrasound and mammography are complementary, rather than competitive imaging techniques. He said that there is no strict age limit for ultrasound; rather its usefulness will depend on both the size of the breast and the density of the tissue (which is related to age). In his center, they are using ultrasound for screening, but this led to an active discussion among participants. Dr. Lehman, Assistant Professor of Radiology at the University of Washington in Seattle, U.S.A., commented that published studies do not support the value of ultrasound for screening as it does not detect nonpalpable masses that could not also be detected by CBE.

*Quality control systems for breast imaging.* Dr. Lehman spoke about the purpose of quality control (QC) systems and the basic mechanisms, giving examples from the American experience. The purpose of QC systems is to increase effectiveness, reduce variability, and minimize waste of resources. The 1992 Mammography Quality Standards Act set specific measurable criteria for radiologists and facilities that could be documented and checked. The program began as a voluntary one and became mandatory. It involved professional societies (like the American College of Radiology) working with government agencies to develop the standards. The burden of financing the program is shared among government agencies, facilities, and individual specialists.

In the discussion afterwards, the value of double-reading of films was raised. Dr. Lehman acknowledged that it does improve quality, but it may not be possible in rural communities where there is only one radiologist. In response to a question about digital mammography, Dr. Lehman said that only one type of digital unit in the United States is approved for screening, although many have been approved for diagnosis. Someone from Kherson said they had bought a digital mammography unit from Kharkiv; they find it is useful for finding larger masses and for localizing a biopsy, but it is not effective in finding microcalcifications and smaller masses.

## **Pathology**

*Current situation and minimum standards.* Dr. Moloshok, Chief of Oncology Department, Chernihiv Oblast Bureau of Pathology, commented on the need for a team of specialists (mammography, ultrasound, cytology, and pathology) to investigate suspicious breast findings. The current system of having pathologists work in bureaus separate from the oncology hospitals reduces the opportunity for pathologists to interact on a regular basis with their oncologist colleagues. Although there are difficulties with the quality of fine needle aspiration (FNA) biopsies and surgical biopsies are much more informative, she recognized that surgical biopsies are much more traumatic for the women. The increase in needle biopsies (both FNA and core needles) is a positive trend, since it will reduce costs and help women. An important role of the pathologist is to give feedback to the surgeon on the quality of the biopsy specimen. She listed eight elements that ought to be included on every pathology report.

*Quality control strategy.* Dr. Zakhartseva, Chief of Pathology at Kyiv City Oncology Center, stressed the importance of sampling at least 10 nodes. Since the choice of therapy will depend heavily on the stage and type of tumor, careful pathology is critical. She highlighted the importance of educating surgeons and oncologists about the value and possibilities of pathology and encouraging them to request a detailed pathology diagnosis, not just malignant or benign. She also supported the idea of having at least one reference laboratory for Ukraine where immunocytochemistry tests can be implemented.

## **Cancer Registry Data**

Dr. Fedorenko, Chief of the Organization and Methodology Department of the Institute of Oncology and Radiology, reported that there are about 14,500 new cases of breast cancer each year, with an age-standardized rate of 36.7 cases/100,000 women in 1998. There has been no detectable effect of the Chernobyl nuclear disaster on breast cancer rates yet. The Registry database is now functioning well, and she considers it to be much more accurate than the paper records reported to the MOH. Overall, the cancer rates in the country are rising, and they project the same trend to be true of breast cancer. Dr. Gulak of the Cancer Registry noted the importance of controlling the quality of the data in the Registry by using, for example, automatic coding of stage based on reported tumor-node-metastasis (TNM) indices rather than having different clinicians recording the stage. Since doctors are still penalized by the MOH for reporting late-stage diagnoses, there is an incentive to shift to earlier stages in reports. Dr. Fedorenko noted that mortality within a year of diagnosis is a more reliable indicator of stage. Accuracy of staging information is important for those trying to evaluate the success of early detection efforts.

## **What is a Feasible Early Detection Strategy for Ukraine?**

Dr. Tsu presented a brief summary of the strategy proposed by PATH (the full paper, Attachment B, was distributed to participants beforehand). Given the current Ukrainian breast cancer epidemiology and resources, the proposed strategy relies on **annual clinical breast exam** for all women aged 35 and older, done in health facilities right in the communities where women live. **Monthly breast self-examination** is suggested as a way of increasing public awareness of the importance of early detection and enhancing women's sense of responsibility for protecting

their own health. Existing mammography and ultrasound units should be focused on **diagnostic imaging** (rather than screening) until all needs for evaluating abnormal CBE results are met. **National guidelines for pathology services** related to breast cancer are needed, including routine hormone receptor testing, as soon as possible.

A lively discussion followed, in which people expressed strong support for the idea of CBE as the primary mode of screening for the time being. A few people expressed a desire to have at least a few institutions continue to do mammography screening; this is feasible as long as women needing diagnostic evaluation at these institutions are already adequately served. Dr. Neiman, Chief of Mammology Center at the Kyiv City Oncology Center noted that the old system of screening at the primary care level followed by referral to the raion oncologist was a good one, but it has become weaker. He called for strengthening the role of the raion oncologists so that they perform a good CBE before a woman is referred to the oncology hospital. He suggested that schoolgirls should be encouraged to do BSE. Dr. Tsu cautioned that this could lead to a great many unnecessary investigations that are traumatic and use up scarce resources, since the rate of cancer among women younger than 35 is very low in Ukraine. Dr. Drozdov, Chief of the Surgical Department at Kyiv City Oncology Center, said that they rely on a team approach for diagnosis already, including ultrasound and pathology. He emphasized the importance of strong referral links so that treatment is carried out in oncology hospitals. Dr. Zakhartseva suggested that it may not be feasible to have use of hormone receptor tests in every center so it may be necessary to have a few laboratories serving as reference centers for this. Dr. Fedorenko stressed that Ukraine can move forward with CBE now, and that if it does so there will be a big improvement in earlier detection.

### **Planning for the Future (Small Group Work)**

Dr. Gamazina reviewed the planning worksheet (handed out to participants) which suggested the steps needed in each of the eight component areas. Participants were asked to consider these steps in their small group work. Results of the small groups of Day 1 and Day 2 are briefly summarized below.

*Financing.* This group concluded that it is impossible at this time to finance a full-scale national program. However, they suggest that certain oblasts may have the resources to get started. For example, the Kyiv City Diagnostic Center just received a research grant of which Hrv. 200,000 will be for mammography film. Other funding sources could include sponsors (such as enterprises, Ukrainians living abroad, churches), commercial or private services (although there is some difficulty getting licenses), payment for services in the public sector (prohibited for the most part but some have found ways), and insurance.

*Data for monitoring and evaluation.* Clear definitions of terms are needed to ensure comparability. It is necessary to fix the language on cancer registration forms to get better information on cancers identified during screening. Stronger links are needed between the routine health information system and the cancer registry system, so that data are shared in a timely way and are analyzed to provide feedback useful to program managers. Since stage data are still not reliable, it is probably best to use cancer mortality or mortality within one year of

diagnosis when evaluating the success of screening programs. It will be important to look at trends over time rather than just one or two years of data.

*Provider awareness and training.* One of the challenges in training providers is the difficulty of bringing them into centers now. Although Dr. Zotov suggested that CBE training should be done at oncology hospitals where special aids can be used and trainees can work with patients with real tumors, others questioned the feasibility of such special centers. Much can still be accomplished through raion-level training—for example, using a video—by master trainers trained at higher levels. The activities of breast cancer survivor groups can help build awareness among providers of the value of screening. There was discussion at several points during the meeting about the need for a specialty of “doctor/mammologist” and for special “mammology centers.” While this might be one way to create a more multidisciplinary approach to breast care, there are significant bureaucratic hurdles with this approach.

*Estimating program targets and capacity.* This group agreed, after some discussion, that the priority target group should remain at women aged 35 to 64, based on their rates of cancer and the life expectancy of women in Ukraine. In terms of identifying the eligible women in a community, it seems that this is easier to do in rural areas, where feldshers know their populations in detail, than it is in urban areas. Theoretically, gynecologists in polyclinics are also supposed to have a list of women for their area or at least know how many there are (so they could estimate the denominator for a calculation of coverage), but participants in the small group were not certain that such information is now available to gynecologists in towns and cities. Raion health authorities may have to seek age-specific population figures from the raion or oblast civil administration or statistics bureau for planning and evaluation purposes.

*Training for mammography and ultrasound.* The group agreed that radiologists responsible for mammography need specialized refresher (or initial) training and recommended that the American College of Radiology BI-RADS terminology be adopted as the standard in Ukraine. Since the manual has recently been translated into Russian and will soon be published by the UAR, it can be incorporated into any new courses. A special course to certify technologists in mammography is needed and should be established at a few qualified centers. The group agreed that ultrasound imaging needs to be part of the diagnostic process and suggested that radiologists should be encouraged to receive training in breast ultrasound.

*Building public awareness.* The group reviewed the items in the planning worksheet and agreed with the basic components. They suggested that the oblast anticancer commission should serve as coordinator, and that raion-level anticancer commissions can be the focal point at that level. Local administrative authorities and nongovernmental organizations should also be involved. There should be an advisory council that includes people like the head of the education department and the chairman of the local television station; even though some of the senior people will probably send a delegate to meetings, it is important to have their involvement, at least in name. The oblast health education centers can be responsible for printing and distributing materials. It was suggested that in addition to use of mass media, booklets, and lectures to women’s groups, a “Ukraine Against Breast Cancer” Day should be organized. While some people suggested a day is not enough, others felt it was a good start and would require a planning group and careful organization. The American and Canadian “Race for the Cure” events were

cited as ways to raise awareness and raise money through company sponsors. The role of survivor groups in raising public awareness was also suggested.

## **Final Discussion and Recommendations**

The final sessions on coordination and local and national planning were combined with a session to develop recommendations. The discussion touched on six basic aspects.

1. *Early detection strategy.* The group went through the elements and agreed with the following:
  - Breast cancer is a serious problem for Ukraine, and early detection is the best answer.
  - Clinical breast exam (CBE) should be the primary screening method for now.
    - CBE training is needed for gynecologists, midwives, feldshers, raion oncologists, and raion gynecologists.
    - The priority target group for annual CBE is women aged 35-69.
    - A system for tracking both the numbers and the results of CBEs is needed.
  - High quality diagnosis is essential follow-up for women with abnormal CBE.
    - Existing mammography equipment should be used first for diagnostic purposes, and only for screening when all diagnostic needs are met.
    - Ultrasound should be a routine part of the diagnostic process, to rule out cysts and to guide needle biopsies.
    - National guidelines for pathology services are needed and should include routine use of hormone receptor tests as soon as possible.

There was not full agreement on whether coordination of the early detection program should be led by the oncology hospital, special breast health centers, or the oblast health administration. Most likely, it will have to be some combination of these forces.

2. *Training.* The group made the following recommendations:
  - The MOH is asked to work towards getting the CBE training module incorporated into medical school curricula and postgraduate courses for gynecologists, surgeons, and oncologists.
  - PATH is asked to provide the MOH with copies of its training resources for CBE and mammography (curricula, slides, and other teaching aids) and lists of master trainers who were trained during the PATH project.
  - A special certificate course on mammography should be established for radiology technologists at designated training centers (where mammography equipment is available). Within three years, all technologists doing mammography should be certified.

- An advanced certificate course on mammography should be established for radiologists at designated centers (where modern mammography equipment is available). Within three years, all radiologists doing mammography should be certified.
  - A clinical base for training in breast ultrasound should be identified. Mammography and ultrasound training should be combined and offered to radiologists.
  - Certain pathology centers should be designated as training and reference centers for breast pathology.
3. *Equipment.* The main recommendation in this area was to repeat the national inventory of mammography equipment, including an expert inspection to determine whether the equipment is functional and safe. Once that is complete, plans to redistribute equipment should be made based on utilization, need, and availability of skilled users.
4. *Public awareness.* Recommendations dealt with both routine and special efforts.
- Oblast health education centers should have the primary responsibility for distributing educational materials.
  - The Department for Coordination of Health Centers at the Institute of Public Health should be responsible for developing or adapting any new materials needed.
  - A small planning group should decide on the feasibility of a one-day national or regional breast cancer event.
5. *Data for monitoring.* There was agreement that, although it is a long process, it is better to try to change the current health information system to track CBEs done in the primary care system, rather than create a separate tracking system. This should be discussed with the Department of Medical Statistics at both oblasts and at the national level. This may require a joint effort between the MOH Women's and Children's Health departments and the Cancer Registry.
6. *Changing policy.* There was a lively debate about the best tactics for changing policy and the roles of different groups in this process.
- There was considerable discussion about how to do this, in particular, whether to call for a national early detection program, just to develop national recommendations, or to have the MOH issue an official order (*Prikaz*) prescribing what should be done. The disadvantages of asking for a national program are that it requires Cabinet Minister's approval and a budget and could take four to five years to be approved. Having a set of recommendations developed by a national working group would help both the MOH and oblast authorities in setting policy. Several people from oblast positions called for a MOH order, because it would make it easier for them to get support for the strategy at the local level if there were an official order in place.

- Although it is already official policy that women should have clinical breast examinations, it is necessary to make changes to ensure that health workers are trained to do them properly and that a system for tracking them is in place.
- Some participants still wanted to call for an order to establish special breast health (mammology) centers.
- Dr. Antonenkova of the MOH asked participants to form a working group, with subgroups focusing on specialty areas, to pull together a consensus set of recommendations to present to the MOH. Participants agreed this could be done in the next month or so, building on the discussion of this meeting, but that the group would need to include a few additional people who had not been able to take part in the meeting. Dr. Zotov and Dr. Babiy agreed to convene the first meeting of the working group.
- Dr. Antonov, Chief of the Dnipropetrovsk Oblast Oncology Hospital Mammological Center, recommended that an association of “mammology” (breast health) be created to bring together all the different specialists dealing with breast disease. As a nongovernmental organization, such a group could advocate for policy change as well as disseminate new knowledge and approaches. There was broad support for this idea among the participants.

*Conclusion.* The active involvement of the participants in three days of intense presentations and discussions was clear evidence of the dedication and commitment of those present to improving the health of Ukraine’s women. Participants thanked PATH for organizing the meeting and expressed their firm resolve to work together to strengthen the breast cancer early detection program using a strategy that was suited to the needs and available resources in the country.

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**Early Detection of Breast Cancer in Ukraine**  
*Strategies and Lessons Learned for Future Planning*  
*PATH Workshop, September 13-15, 2000*

**AGENDA**

**September 13**

- 9:30 -10:00    *Registration, coffee/tea*
- 10:00-10:30    *Welcome and introduction to workshop*  
 MOH interest in BC, commitment to early detection    Irkina T.K.  
 USAID's goals in BC project    O Radziyevska  
 PATH purpose of workshop, review of  
 agenda and handouts    Gamazina K. O.
- 10:30-11:15    *Review of key components of early detection*    V. Tsu
- 11:15-1:00    *Current and planned activities in Ukraine: Lessons and challenges*  
 Chernihiv    Zotov V. M.  
 Lviv    Gutsal L. A., Kens A.A.  
 Odesa    Voityshyn V. B.  
 Kyiv, Left Bank    Yatsuk O.S.
- 1:00-2:00    *Lunch*
- 2:00-3:25    *(Current and planned activities in Ukraine: Lessons and challenges*  
*continuation with other oblasts)*  
 Dneipropetrovsk    Antonov S.M.  
 Donetsk    B'elonenko G.A.  
 Kherson    Miakinkov V.B.  
 Chernivtsi    Kryvchansky I. M.
- 3:25-3:30    *Explain small working groups*
- 3:30-3:45    *Coffee/tea break*
- 3:45-4:30    *Small working groups*  
 Group A: Possible financing strategies for  
 various components    Babiy Ya. S.  
 Group B: Data for monitoring and evaluation    Fedorenko Z. P.  
 Group C: Building provider awareness    Gutsal L. A.
- 4:30-5:30    *Report back from small groups and discussion*

September 14

	<i>Detection and diagnosis methods</i>	
9:00-9:45	<u>Clinical Breast Exam</u>	
9:00-9:15	Training strategies and resources	Khokhlich T. I.
9:15-9:30	Monitoring for coverage and effectiveness	Gamazina K. O.
9:30-9:45	Mobilizing health workers	Zotov V. M.
9:45-11:10	<u>Breast Imaging</u>	
9:45-10:00	Mammography: current resources and future prospects	Babiy Ya. S.
10:00-10:15	Ultrasound: current resources and future prospects	Bilonenko G.A.
10:15-10:30	<i>Coffee/tea</i>	
10:30-11:10	<i>Quality control systems for breast imaging</i>	Lehman C.
11:10-11:30	<i>Pathology for completing the diagnosis: minimum standards, current situation, quality control strategy</i>	Zakhartseva L. M.
11:30-12:30	<i>Panel: What is a feasible detection/diagnosis strategy for Ukraine?</i>	
	<i>Planning for the future</i>	
12:30-1:00	Planning process; set-up for small groups	Gamazina K. O.
1:00-2:00	<i>Lunch</i>	
2:00-2:45	<i>Small working groups</i>	
	Group A: Estimating program targets and capacity	Gulak L.O., Tsu V.
	Group B: Training for mammo and US	Babiy Ya. S., Lehman C.
	Group C: Building public awareness	Zotov V. M.
2:45-3:15	<i>Report back recommendations</i>	
3:15-4:00	<i>Coordination within and between different levels:</i>	
	Within raion and oblast	Zotov V. M.
	National – MOH	Fedorenko Z. P.
	<i>Discussion</i>	
4:00-4:15	<i>Coffee/tea</i>	
4:15-5:00	<i>Small working teams: Refining local and national plans</i>	

September 15

- 9:00-10:30 *Report back and discussion*
- 10:30-10:45 *Coffee/tea*
- 10:45-11:30 *Develop recommendations - list of actions needed  
at different levels, who is responsible, suggested timetable*
- 11:30 – 12:00 *Wrap-up*
- 12:45-1:00 *Administrative details (travel, receipts, miscellaneous)*
- 1:00-2:00 *Lunch; farewells*

**Early Detection of Breast Cancer in Ukraine**  
**Strategies and Lessons Learned for Future Planning**  
**PATH Workshop, September 13-15, 2000**

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## Clinical Breast Examination as the Primary Breast Cancer Screening Tool for Ukraine (2000-2005)

### PATH Position Paper

September 2000

#### Background

*Epidemiology.* Breast cancer is the leading cause of cancer death among women in Ukraine. In 1998 (the latest available figures) there were 14,615 new cases and more than 8,000 deaths nationally, an increase in incidence of 6.4% in the 7 years since 1992. The crude incidence rate (per 100,000 women) was 54.3, while the age-standardized rate was 36.6. This compares with a crude rate of 115.4 and an age-standardized rate of 94.6 in the United States in 1997 (SEER Cancer Statistics Review, 1973-1997). The rate varies widely within Ukraine (see Figure 1, attached), even when considering the different age distributions, from a low age-standardized rate of 27.2 in Zakarpattia oblast in 1998 to a high age-standardized rate of 53.3 in Odesa oblast. Incidence rates are highest among women aged 60-64 (137.9/100,000), but they first climb above 100/100,000 among women aged 45-49 and remain elevated through age 79 (see Figure 2, attached, with examples from several high- and low-incidence regions). More than 70% of cases in Ukraine occur among women 50 years old or more, with another 20% among women 40-49. Only 2% of cases occur among women younger than 35 years.

It is well known that early detection of breast cancer has a big impact on treatment and survival for women ages 50 and above. About one-third of new cases in Ukraine are identified only in the late stages (III and IV), when regional or distant spread has already occurred and treatment is less effective (compared with about 9% of new cases in the United States). Only about 12% of new cases in 1998 were identified in Stage I, when treatment is most successful and least traumatic (compared with about 40% in the United States).

*Current breast cancer screening and diagnostic practices in Ukraine.* Of the three possible methods for screening for breast cancer, only clinical breast examination (CBE) has been routinely promoted in Ukraine. Although CBE is supposed to be a regular part of women's health care, there are no data on how many women actually receive CBE annually nor on the results of such examinations. Both doctors and nurses report that they receive no special training on how to conduct proper CBE. However, in selected areas, more than 1000 health workers have recently been trained using the new curriculum developed by PATH. With the economic difficulties of recent years, the number of women seeking preventive care (or any care) has reportedly declined, so the opportunities for CBE are decreasing. Even when CBE is done and an abnormal result is found, women are often unable or unwilling to get further diagnostic evaluation and appropriate treatment.

Monthly breast self-examination (BSE), another possible technique for finding cancer earlier, is not widely known or practiced in Ukraine. Health workers have not been trained in methods for teaching BSE to women. As a result of special projects, there are now materials available for explaining and promoting BSE, although the quantity is limited.

Screening mammography is carried out on a very small scale in Ukraine, primarily because of very limited mammography equipment and supplies. A recent review by the Ukrainian Association of Radiologists (1998) found that in the 17 oblasts surveyed (which did not include Kyiv, Kharkiv or Sebastopol) there were only 134 functioning mammography machines. Less than 10% of these were modern machines (although a few new machines have been added since that time). The report also concluded that few radiologists have good skills in reading *screening* mammograms, due to the lack of specialized training or sufficient experience. Similarly, few radiologic technologists have received specialized training in mammography, although a new three-day curriculum is now available (along with a handful of trainers).

Mammography has several important roles in the *diagnostic* process also, along with ultrasound. Most mammography is currently performed for women with suspicious lumps identified by doctors or the women themselves. However, its use for guiding biopsy (wire localization) or for checking post-biopsy is quite limited. Ultrasound is more widely available, but not always with the correct probe. A few specialists have received training in ultrasound-guided needle biopsy, but the supply of appropriate needles is inadequate.

While some fine needle aspiration biopsies are done, most biopsies consist of frozen sections performed on surgically obtained specimens. Pathology supplies and equipment for histologic analysis are in short supply or poor condition at many cancer hospitals. Tests for hormone receptors and pathologists trained to use them exist at only a few centers such as Kyiv, Lviv, and Chernihiv.

*Practices in other countries.* In 22 industrialized countries surveyed in 1995 (where rates of breast cancer tend to be higher than in Ukraine), screening by mammography was the standard (three also use CBE, and four add CBE and BSE). The eligible age groups and screening intervals varied, as did the rates of coverage achieved. Countries with lower breast cancer rates and/or limited health care resources do not generally attempt screening mammography programs.

### Proposed Approach

Given the current Ukrainian breast cancer epidemiology and resources, the strategy proposed to begin advances in screening for this country relies on **annual clinical breast exam** for all women aged 35 and older by trained medical workers (preferably female). This should be done by midwives, feldshers, and gynecologists at health facilities right in the communities where women live. Training for those responsible for screening should include basic information on the biology and current survival rates, the range of breast findings that might be related to an abnormal CBE, and the treatment options women might face. This will enable them to properly inform women and to reduce unwarranted anxiety. All other medical workers should take an active role in asking women whether they have been screened by clinical breast examination that year and encouraging them to do so if they have not been. **Monthly breast self-examination** should be promoted as a way of increasing public awareness of the importance of early detection and increasing individual acceptance of a woman's role to protect her own health by both BSE and CBE. There are no good studies showing a decrease in mortality due to regular BSE, but it may be helpful as an educational tool. A system for tracking coverage of the eligible population

with CBE and for assuring that those with abnormal exams receive diagnostic evaluation and treatment, if needed, should be established.

Existing mammography units and any new capacity should be focused on **diagnostic imaging** needs (rather than screening) until the infrastructure and resources are in place so that all women with abnormal CBEs can be adequately evaluated. Each oncodispenser or metropolitan diagnostic center should have at least one modern mammography machine and ultrasound with MHz7.5 probe. The use of ultrasound to rule out cysts will reduce the number of biopsies needed, and its use to guide fine needle aspiration or core needle biopsies will improve their quality. **National guidelines for pathology services** related to breast cancer should be reviewed and/or instituted. Hormone receptor testing should become a routine part of the pathologic analysis as soon as possible, since the information will greatly aid in the choice of therapies.

Once CBE is widely and effectively practiced and surplus mammographic capacity exists (that is, after all women with abnormal CBEs are receiving appropriate diagnostic evaluation), then a screening mammography program targeted at women 45-69 years old could be *added* to the CBE program. Special priority for mammographic screening should be given to the three areas with the highest incidence rates, according to 1999 Cancer Registry data (the cities of Sebastopol and Kyiv and Odesa oblast), where screening mammography will be most cost-effective.

#### Rationale for CBE-based Approach

There are several important reasons why Ukraine should consider an approach based on CBE rather than mammography at the present time. These relate primarily to the cost-effectiveness of different strategies, which depends in turn on the local epidemiology, the performance of various screening tests, existing infrastructure and resources, and the capital and recurrent costs associated with different approaches. Given the variability within the country, those oblasts or cities with the highest incidence rates or with greater financial resources might be ready to add a mammography-based component sooner than the rest of the country.

- **Clinical breast exam (CBE) is moderately sensitive and highly specific.** The sensitivity of CBE is dependent on the skill of the medical worker, the size and density of the breast, and the size of prevalent tumors. One meta-analysis (Barton et al, 1999) found the sensitivity of CBE to be 54% and the specificity 94%. Studies in Canada (Baines et al, 1989), Japan (Morimoto et al, 1997; Ohuchi et al, 1995; Kanemura et al, 1999) and the U.S. (Bobo et al, 2000) have reported CBE sensitivity levels of about 50-85%, with higher rates for women in their 40s and declining somewhat for older women. Specificity was somewhat higher for women 50 and older. Since there has been little screening in recent years, there is a higher rate of larger tumors prevalent in the population of Ukraine. Such tumors can be as easily detected by CBE as by mammography. CBE can also detect many small tumors, when done properly. In the U.S. study (Barton et al, 1999), based on 752,081 CBEs from 1995-98, 25% of the cancers identified were *in situ*.
- **Mammography detects 31-64% more cancer cases than CBE, but at a cost 500-800% higher.** The ability of mammography to detect cancer depends on many factors: quality of equipment and film, skill of technologist and radiologist, breast density (Mandelson et al,

2000), and size of prevalent tumors. A recent meta-analysis of mammography (based on studies from Sweden, Canada, Netherlands, and USA) found that sensitivity ranged from 83% to 95%, and specificity from 93.5% to 99.1% (Mushlin et al, 1998). Based on the three studies that included women 40-49, it appears that sensitivity for women in their 40s is about 10 percentage points lower than for women 50-59 (Mushlin et al, 1998). Most units in Ukraine would not have such good conditions at present and should expect somewhat lower sensitivity. In addition, breast density in Ukraine tends to be greater, further reducing expected sensitivity.

**Table 1. Screening Cost per Breast Cancer Case Detected**

Screening model	Incidence Level/100,000		
	70	100	150
CBE (55%)/MM \$5	\$19.92	\$13.96	\$9.32
CBE (65%)/MM \$5	\$16.87	\$11.82	\$7.90
MM \$5	\$92.44	\$64.71	\$43.14
CBE (55%)/MM \$8	\$23.93	\$16.77	\$11.21
MM \$8	\$147.90	\$103.53	\$69.02

Table 1 shows sample costs based on assumptions of CBE costs of \$0.50 (labor) followed by mammography for those with abnormal exams, with mammography costs estimated at two different levels (\$5 and \$8). This only counts the recurrent costs (labor, supplies) of mammography. It assumes CBE sensitivity levels of 55% and 65% and MM sensitivity of 85% (and 98% after abnormal CBE). It assumes 5% of CBEs will be abnormal and 10% of screening MMs will need additional mammography.

- **The screening cost per cancer case detected is higher when incidence is lower.** Using Table 1 again, we see the cost per case detected for 3 levels of incidence (typical of different oblasts and age groups in Ukraine). While the cost per case detected increases for both mammography (MM) and clinical breast exam (CBE) as incidence declines, the premium (added cost) for MM over CBE increases much more (\$73 extra versus \$34 extra) at low incidence.
- **The incidence rate among women under 35 is too low to justify active screening.** Incidence rates among women 30-34 ranged from 0 to 20.9 per 100,000 in 1999. Even with CBE's high specificity (95%), approximately 5000 women would have abnormal CBEs and the associated diagnostic evaluations to find 6-12 expected cancers. The cost to the health care system and the cost, distress and trauma for the healthy women is unwarranted.
- **Mammography has much higher capital (as well as recurrent) costs than CBE.** One mammography machine (which can screen about 6,000 women per year if fully utilized) costs about \$50,000-\$80,000. An additional \$10,000-\$15,000 is needed for a film processor and accessory equipment. The initial MM training for radiologists and technologists is far more expensive than that for CBE, although fewer people would have to be trained. Ukraine has nearly 8 million women aged 45-69 (about 16% of the total population), which would

require 1320 mammography units, plus about 10% more for diagnostic evaluation (1450 minus the 50 or so already available). At \$60,000 each, the 1400 units needed (in addition to existing modern machines) would cost approximately \$84 million. If refurbished units were purchased at \$20,000-\$30,000 each, the cost could be reduced to \$28-\$42 million.

- **CBE is better suited to rural populations and small towns than MM.** MM requires concentrated numbers to assure efficient utilization of the equipment and to enable radiologists to maintain their interpretive skills. When transport is difficult (as it is now in Ukraine), only CBE can be brought to locations convenient to rural and town populations.
- **Most of the resources to get started with CBE already exist.** Ukraine has an excellent system of health facilities at the community level (FAPs and polyclinics) and good referral links. These facilities are staffed by people who can learn effective CBE and who would be acceptable to women. The policy and tradition of CBE is well established. A new 1-day CBE curriculum and several master trainers for CBE are available to give refresher training to midwives, feldshers, gynecologists, and oncologists. Funds are needed to reproduce training materials, and the health information system needs some modifications to enable proper monitoring of the early detection program.
- **Mammography capacity is very limited; priority should be given to diagnostic use.** Those women with an abnormal CBE must be assured of getting an effective diagnostic evaluation, with high quality mammography, ultrasound and biopsy. They should have get priority (over screening clients) as long as mammography capacity is inadequate.

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# Захворюваність на рак молочної залози, Україна, 1999

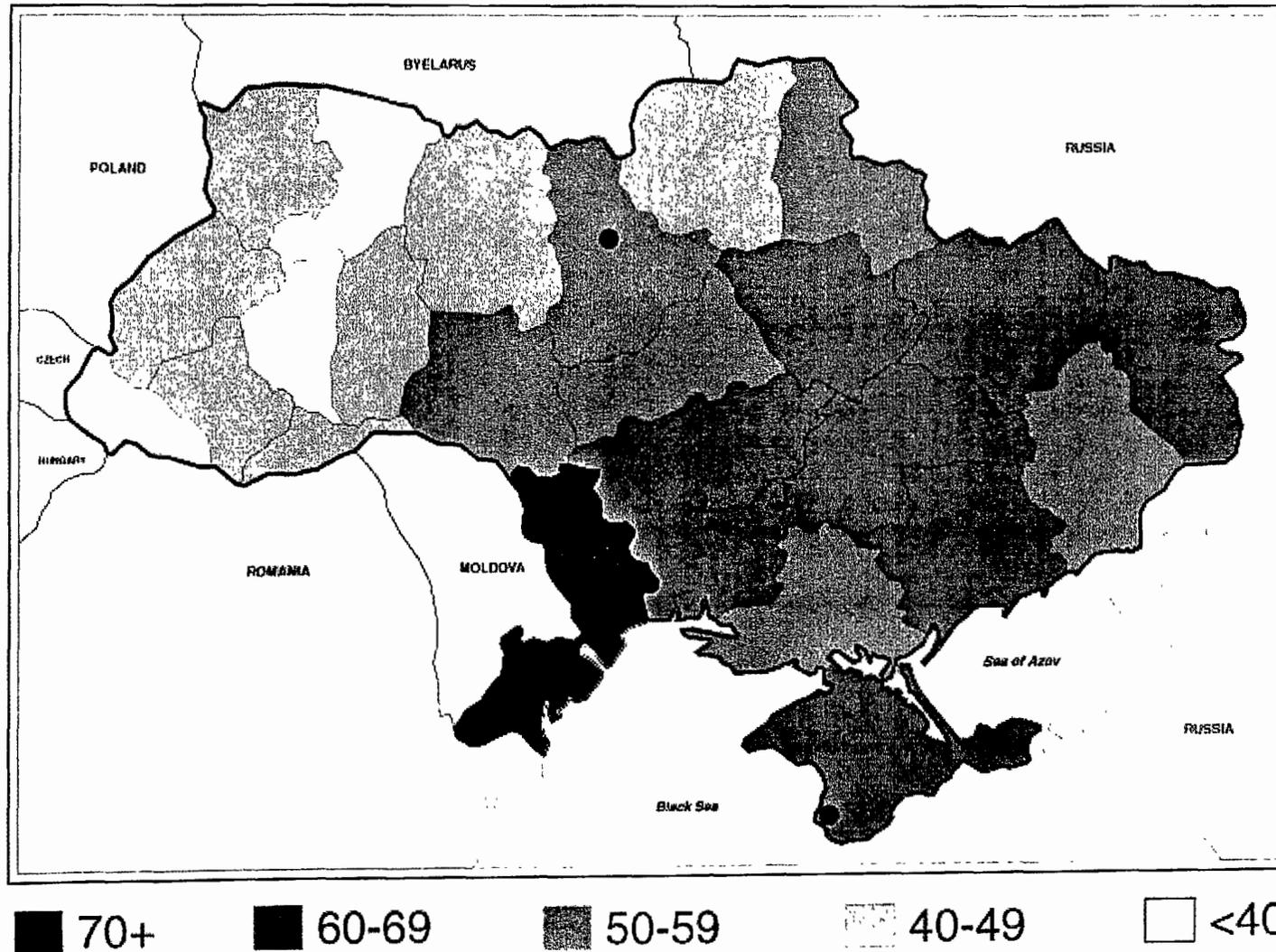
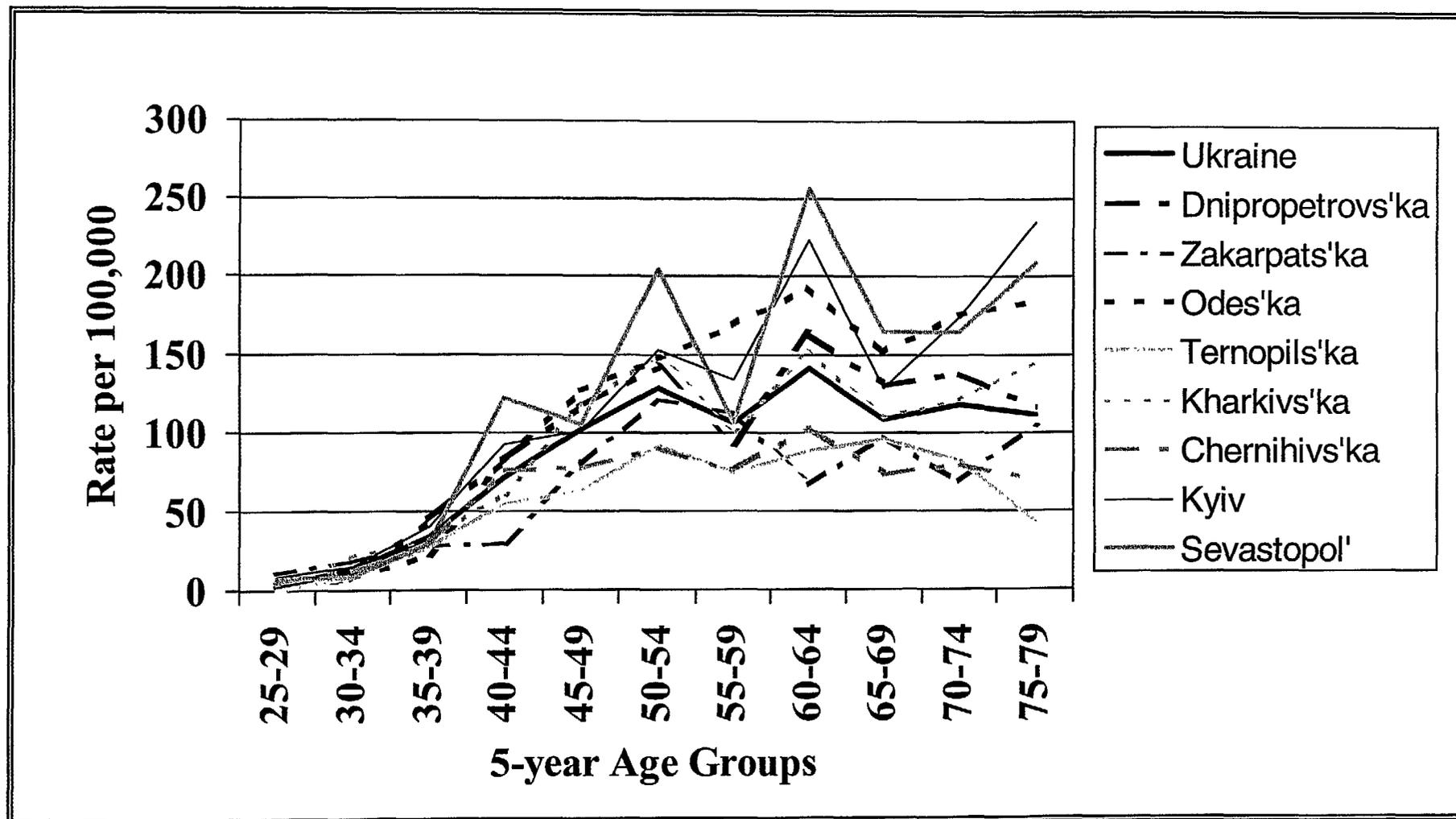


Figure 2: Age-specific Breast Cancer Incidence  
Ukraine and Selected Regions, 1999



**Attachment H**

**Position Paper #2: One View Vs. Two Views  
In Screening Mammography**

# One-View Vs. Two-Views In Screening Mammography

## PATH Position Paper

September 2000

### Issue

Screening mammography can be done with one mediolateral oblique view of each breast or with two views (adding the craniocaudal view). What is the gain in sensitivity associated with the extra view? What is the magnitude of any other benefit or disadvantage? What are the differences in cost between one view and two? Do these benefits and costs differ among sub-groups of the population? To what extent are they affected by other factors? This paper will present information from the scientific literature with regard to these questions so that Ukraine health policy makers can weigh the costs and benefits and determine which policy is best for its current situation.

### Background

The mediolateral oblique (MLO) view is considered the most informative single view, since it shows the greatest amount of breast tissue and includes the deepest part of the breast in the axillary tail region of the upper outer quadrant (Sickles et al, 1986). Among those countries that carry out screening mammography, many (such as the United States) use two views for both primary (prevalent) screening and for all subsequent (incident) screens. Others (such as the U.K. and Netherlands) use two views for the primary screen but then use a single MLO view for subsequent screens for some or all women. In Sweden the practice has varied by age, with women aged 40-54 having two views and older women having one view (Thurfjell, 1994). Several studies have been undertaken to determine the benefits and costs of the various screening strategies, using outcomes such as the sensitivity (or detection rate), the rate of recall for additional assessment, and the predictive value of positive screens (e.g., positive and negative biopsy rates). Costs have been measured in financial terms, such as mammography costs, assessment costs, patient costs and cost-effectiveness ratios, and in health terms, such as radiation exposure.

### What is the gain in sensitivity associated with the extra view?

Overall, the gain is relatively small. In a review of 19 studies van Dijck et al (1992) found that the difference in sensitivity achieved by adding a second view ranged from 5.7% lower to 19.4% higher. Studies done since then have shown only modest improvements in sensitivity, such as 0.2% in Sweden (Thurfjell et al, 1994), 8% in U.K. (Wald et al, 1995), and 6% in U.K. (Warren et al, 1996). Below we describe how these improvements might affect cancer detection in Ukraine.

### **What is the magnitude of any other health benefit or disadvantage?**

Some studies report slightly better specificity, but results are mixed. The review by van Dijk et al (1992) reported improvements in specificity that ranged from 2.7% to 36.1%. In a study of 12,636 Swedish women, Thurfjell et al (1994) reported only a very slight increase in specificity (97.2% for 2-view versus 95.7% for 1-view). However, in a selected set of cases (60% cancers) the improvement in specificity was 16% (Thurfjell, 1994). Wald et al (1995) also reported only a very slight increase of about 1%. Another British screening study (Warren et al, 1996) reported a 2.3% increase in specificity (91.9% versus 94.2%). In a review of Dutch screening results, specificity is not available but the predictive value of positive films was similar (about 50%) for both 1-view and 2-view (Fracheboud et al, 1998). While two studies found a lower recall rate with 2 views (Wald et al, 1995; Warren et al, 1996), three studies found higher biopsy rates with 2 views (9% more in Sickles et al, 1986; 18% in Thurfjell et al, 1994; 23% more in Warren et al, 1996).

There may be a very slight increased risk due to extra radiation exposure with 2 views. Wald et al (1995) estimated the risk at 1-2 cancers/100,000 women after 5 screens with 2 views. Such risks are based on hypothetical calculations, and others have suggested a much lower risk for mammography in general (Feig, 1994). In some parts of Ukraine, where radiation exposure has already been higher than usual, such extra exposure (although the risks are slight) may be more of a consideration.

### **What are the differences in cost between one view and two?**

Local costs are variable and depend on many factors. In addition to the cost of film and chemicals, the time of the radiologist and technologist must be considered. The cost of follow-up assessment (further films, ultrasound, biopsy) is important if recall rates and specificity differ by much. If out-of-pocket costs for film, chemicals and mammography unit maintenance are more important than the fixed costs of staff time, then the incremental cost of the second view is proportionately more important. Similarly, if the overall rate of positives is relatively low, then the reduction in assessment costs due to better specificity will not be enough to compensate for the additional film and other costs. For example, Wald et al (1995) estimated that costs for the second view were 24% higher than for 1-view. Bryan et al (1995) found that the reduction in recall rate in the U.K. associated with 2-view screening was still not sufficient to offset the increased costs of the second view, estimated at £3.63 per patient.

With regard to film use, the difference is fairly constant. Regardless of different assumptions about sensitivity and specificity, the ratio of films (2-view versus 1-view) needed to detect cancer stays relatively constant. Table 1 shows the theoretical situation for several levels of sensitivity and specificity and several rates of cancer. For example, at a cancer rate of 50, sensitivity of 0.90 and specificity of 0.95, 45 cancers will be found in 209,995 films using 1-view. The projected outcomes assume that those identified as positive after 1 view will need two additional films, while those positive after 2 views will need only one additional film. The comparisons in Group A, using sensitivity and specificity differences similar to many of the published studies, show that the *ratio* of extra films needed to detect each cancer does not

vary with the cancer rate, but the *absolute number* of films needed to detect a cancer is very dependent on the cancer rate. When screening among women 60-64 in Ukraine with 1 view (given these assumptions), one might expect to detect 6.4 cancers using 10,000 films, as opposed to only 1.2 if one screened with 2 views among women 40-44 in most parts of Ukraine. Group B demonstrates that these relationships do not change very much if the sensitivity is lower (as is probably the case in routine practice). Group C illustrates the effect of reducing the specificity, such that the difference is either 7% or 12%; the ratio of extra films needed is reduced only very slightly. Line D shows the combined “worst-case” effect of a 15% difference in sensitivity and 7% difference in specificity.

**Table 1. Impact of cancer rate, sensitivity and specificity on film use**

Cancer Rate per 100,000	Assumptions				Projected Outcomes				
	Sensitivity 1-view	Sensitivity 2-view	Specificity 1-view	Specificity 2-view	Films/ca 1-view	Films/ca 2-view	Ca/10,000 films, 1-view	Ca/10,000 films, 2-view	Ratio of films/ca for 2 vs. 1
<b>A)</b> 50	0.90	0.95	0.95	0.97	4667	8484	2.1	1.2	1.8
100	0.90	0.95	0.95	0.97	2333	4242	4.3	2.4	1.8
150	0.90	0.95	0.95	0.97	1555	2828	6.4	3.5	1.8
<b>B)</b> 50	0.85	0.90	0.95	0.97	4941	8956	2.0	1.1	1.8
100	0.85	0.90	0.95	0.97	2470	4478	4.0	2.2	1.8
150	0.85	0.90	0.95	0.97	1647	2985	6.1	3.3	1.8
<b>C)</b> 100	0.85	0.90	0.90	0.97	2588	4478	3.9	2.2	1.7
100	0.85	0.90	0.85	0.97	2706	4478	3.7	2.2	1.7
<b>D)</b> 100	0.8	0.95	0.90	0.97	2750	4242	3.6	2.4	1.5

The cost per additional case detected is hard to determine for Ukraine. Such costs consist of the local costs for mammography and other assessment procedures, the recall rate, and the underlying cancer rate. The lower the cancer rate, the more expensive it will be to find each additional case. In a cost analysis in the U.K., the cost per additional cancer detected with 2 views varied from £1705-£2959, depending on whether or not double reading was also involved (Johnston, Brown, 1999).

**Do these benefits and costs differ among sub-groups of the population? To what extent are they affected by other factors?**

Certain types of cancers are more likely to be missed by 1 view. Although Blanks et al (1998a) did not find any improvement in the detection of *in situ* cancers with a second view, other studies have shown that smaller invasive cancers are more easily picked up with 2 views (Warren et al, 1996, cancers <20 mm; Blanks et al, 1998b, cancers <15 mm; Given-Wilson, Blanks, 1999, cancers <10 mm). Other characteristics associated with cancers missed on 1 view were benign or round appearance (Given-Wilson, Blanks, 1999), lack of spiculations or microcalcifications and location deep in the center of the breast (Hackshaw et al, 2000). Factors accounting for false positives with 1 view were overlapping normal

structures that simulated a mass on the oblique view or, less commonly, isolated tiny calcific particles projected close together in the oblique view simulating a cluster (Sickles et al, 1986).

Neither breast density nor size has been shown to affect the difference between 1-view and 2-view readings. Although several studies have shown that breast density affects the overall sensitivity of mammography (for example, Kerlikowske et al, 1996; van Gils et al, 1998), neither density nor breast size was related to the cancers missed by 1 view (Thurfjell et al, 1994; Hackshaw et al, 2000).

Differences between prevalent and incident screening rounds may be related to performance or cost, or both. Since incident tumors may be smaller than those found in the first (prevalent) screening round, 2-view screening might be expected to be more effective in incident rounds. However, the presence of an earlier film for comparison may compensate for the smaller tumors and reduce the benefit of the second view (Warren et al, 1996). Furthermore, the much lower rate of cancers in incident rounds will increase the cost per cancer detected.

Double reading of films produces a greater increase in performance than 2 views. Thurfjell (1994) found that sensitivity improved by 9%-22% with pairs of readers, as compared to a 2% increase in sensitivity when a second view was added. In a study of small cancers (<15 mm), Blanks et al (1998b) found that double reading improved detection by 32% when 2 views were available, but by 73% when just 1 view was available. In a study of 43 U.K. screening programs (Johnston, Brown, 1999), where the cost of each additional cancer detected was compared to the base cost of 1-view with single reading, additional cancers detected by double reading of 1-view were £210-366 each while those detected by single reading of 2 views were £2959 each.

## **Conclusions and Recommendations**

While there seems to be a clear benefit from having 2 views, the increase in value seems to be relatively modest and comes at a substantial cost (particularly when initial out-of-pocket costs are important and when rates of cancer are low to moderate, both of which are true for Ukraine). When resources are limited, countries must consider how to allocate them to maximize the benefit to the population as a whole. Of course, the cost to the woman of having her cancer missed is incalculable since it may consist of delaying her treatment until after regional or distant spread has occurred, but resources used to give a few women a slightly better chance of detection may result in many women not being screened at all.

Therefore, PATH makes the following recommendations for consideration in Ukraine:

- Do double reading of 1-view (MLO) screening mammography (where possible) before adding a second view.
- Do everything possible to maximize the quality of 1-view screening mammography, including training for radiologists and technologists, use of good film and processing chemicals, and maintenance of equipment in good working order.

- When more resources become available, consider using two views for the first (prevalent) screening and one view for subsequent (incident) screens, making sure that prior films are consulted for comparison.

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**Attachment I**

**Position Paper #3: Breast Cancer Survivors in Ukraine  
Complementing the Work of Medical Providers**

# **Breast Cancer Survivors in Ukraine: Complementing the Work of Medical Providers**

## **PATH Position Paper**

**September 2000**

### Introduction

Breast cancer is the leading cause of cancer death among women in Ukraine. In 1998, approximately 14,600 new cases were identified and nearly 8,000 women died. Unfortunately, public information and education, in general, are minimal, and consequently, early detection remains an elusive goal, with nearly one-third of new cases in 1998 still being identified in the late stages (III-IV) and only about 12% identified at Stage I. Due to severe economic conditions, medical providers face great challenges in providing early detection services and optimal clinical care for women with this disease, while the psychological and emotional needs of women diagnosed with breast cancer are rarely recognized formally or addressed.

In 1997, the United States Agency for International Development (USAID) supported a three-year Breast Cancer Assistance Program in Ukraine to strengthen early detection, diagnosis, and treatment services in Ukraine. Managed by the Program for Appropriate Technology in Health (PATH), an additional key objective of this program was to improve the quality of life of women experiencing the disease by providing them with information and psychosocial support and by encouraging the formation of community-based breast cancer survivor groups. With support from this program and its local partners (particularly the Kyiv City and Chernihiv Oblast Oncology Hospitals), a nascent breast cancer survivor movement has emerged in Ukraine that has embraced the concepts of self-help and mutual support, greatly empowered the women involved, and ultimately promises to challenge the societal stigmatization of the disease.

In many countries in North America and Europe, breast cancer survivors have led the way in bringing needed attention to the disease. Their efforts have included improving public awareness about the disease; addressing the psychosocial and information needs of newly diagnosed patients and survivors alike; stimulating the medical community to increase attention to issues of quality of life, not just clinical intervention; advocating for legislative changes that protect the rights of patients; and raising breast cancer research funds as well as shaping national research and advocacy agendas. In countries such as Ukraine, where current economic circumstances are extremely difficult, breast cancer survivors have made important progress in the last two years in gaining the confidence of doctors and, in particular, in complementing their efforts in meeting the informational and psychological needs of other women with breast cancer. In addition, by being willing to be public about their illness, they have begun the important process of challenging long-held societal views about cancer and shattering the stigma that surrounds the disease. Finally, and perhaps most important, survivors are effective role models for both healthy and newly diagnosed women by serving as living proof that early detection is critical and that they not only survived breast cancer, but have gone on to live normal, productive lives. Thanks to their efforts, medical providers

in several settings now discuss the diagnosis and treatment options with patients more openly than ever before, thus nurturing a true collaborative patient-provider relationship.

The efforts of breast cancer survivors in Ukraine deserve strong encouragement and support from the medical community and from society as they move ahead. Several specific areas in which their activities need to be supported are described below.

### Providing Psychosocial Support

Research conducted in numerous countries suggests that it is not sufficient to focus solely on the physiologic aspects of breast cancer diagnosis, treatment, and rehabilitation to facilitate recovery. Rather, cancer, in general, is increasingly being framed as a “bio-psycho-social” illness: in addition to the physical manifestations of the disease, a number of psychological reactions have been identified as being commonly associated with diagnosis, treatment, and recovery. These reactions may be mitigated by one’s personality, coping skills, age, family and socioeconomic status, or other factors, but they often include, to varying degrees, fear, anger, guilt, anxiety, depression, denial, and a deep sense of isolation or loneliness.<sup>1</sup> In some studies, 25-30% of mastectomy patients suffered from clinically diagnosed depression and anxiety for up to two years after surgery.<sup>2 3</sup> Other studies suggest that women with breast cancer experience a level of depression twice as high as that found in the cancer-free population.<sup>4 5</sup>

A number of studies provide strong evidence that psychosocial and educational interventions, such as participation in support groups, positively affect cancer patients’ ability to cope with the illness, thus improving their quality of life. One widely quoted study found that long-term survival among breast cancer patients may be linked to psychosocial support.<sup>6</sup>

Specifically, these interventions:

- Reduce psychological distress
- Improve adaptation and coping
- Improve attitude towards the future
- May contribute to faster recovery
- May contribute to longevity

### *Hospital- and Community-based Support Groups*

In at least eight cities\* in Ukraine, breast cancer survivors have started organizing for the purposes of mutual support. For many women with breast cancer, support groups can provide invaluable assistance in normalizing their experience and assuring them that their emotions and reactions are typical and can be managed. Given that breast cancer is rarely discussed publicly, it is especially important that these women have the opportunity to discuss their fears and concerns openly and safely. The medical community can extend its support to these groups in several important ways—at very little, if any, cost. For example, in Chernihiv, thanks to the leadership of the Oblast Oncology Hospital’s Chief Doctor, the dedication of

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\* Chernihiv, Kyiv, Lviv, Zhytomyr, Kherson, Kharkiv, Zaporizhzhia, and Mykolayiv

his staff, and the courage and commitment of breast cancer survivors themselves, a successful model of collaboration to address the psychosocial needs of newly diagnosed women has emerged. In this setting, the hospital has designated space and staff to facilitate the formation and continuation of groups; survivors, patients, and doctors now meet together regularly to offer support and information. In other settings, where groups are community-based, survivors have sought and received permission from oncology hospitals and polyclinics to promote the groups in the wards and have found space, often donated, in which to meet. In addition, doctors have met with groups to provide information on clinical care and to answer questions. In all cases, doctors and nurses play a vital role in the success of these efforts by informing patients about the existence groups and encouraging them to attend.

#### *Outreach to Newly Diagnosed Women*

As the groups have matured and individual members have grown stronger both emotionally and physically, women increasingly have expressed interest in reaching out to newly diagnosed women or others who were isolated or otherwise in need of support. Indeed, a number of women already had had experience visiting the hospital wards informally to meet with patients and to offer them emotional support, recognizing that despite the best intentions of medical providers, they simply did not have the time to take on this role. Similarly, given current economic circumstances, it is not feasible for hospitals to hire social workers, psychologists, or health educators to do this work.

Despite these individual efforts, however, a structured program with formal collaborations with oncology hospitals had not yet been created, and many women expressed the need for specific training in communication and counseling to better prepare them for this work. As a result, in collaboration with PATH staff and local psychologists, a Peer Support Volunteer Program was established, whereby survivors visit oncology wards to provide information and emotional support to newly diagnosed women undergoing treatment, and a comprehensive training curriculum, tailored to the Ukrainian context, was developed. The training is conducted by Ukrainian psychologists from the National Institute of Psychology in Kyiv to ensure that survivors are adequately prepared. Volunteer programs are now active in Chernihiv, Kyiv, Lviv, and Zhytomyr, with plans underway to expand the model to other locations. Where the program is active, support from medical personnel has increased steadily as doctors and nurses experience firsthand how this collaboration with survivors can aid their work.

Similar programs have existed for many years in other countries, and it is a well-established means of providing information and support to newly diagnosed women. The power of this approach lies in the survivors' inherent ability to empathize with and serve as role models for newly diagnosed patients. This effort not only has helped address the immediate psychosocial concerns of newly diagnosed women, but it has served to inform these women about the existence of community-based support groups, which many now join once they have been discharged. This program is an excellent example of the partnership that can be developed between survivors and the medical community to meet the informational and

emotional needs of women with breast cancer in Ukraine.\* The volunteers do not seek to challenge the authority of doctors, but rather, to assist them in their efforts to provide the best care possible to women. Because the program is completely volunteer-based, it is extremely cost-effective. It only requires that medical personnel sufficiently trust the intentions and abilities of survivors in meeting with patients and that they open their doors to those volunteers offering to help.

### Providing Information to Newly Diagnosed Patients

Research among health providers in Chernihiv, Kyiv, and Odesa at the start of the PATH project suggested that women were told their diagnosis only about 20% of the time due to a prevailing belief that women would become more depressed (rather than less), and even suicidal, if told the truth. In contrast, interviews with breast cancer patients strongly suggested that most women wanted more explicit information about their illness and prognosis and about the diagnostic and treatment interventions that were being recommended for them. For many women we interviewed, the known was less frightening than the unknown. Indeed, research from other countries suggests that information gathering can improve a woman's ability to cope with the illness as it may enable her to regain a sense of control and assume some responsibility for her recovery.<sup>7</sup> Clarifying myths and misperceptions and providing accurate information also can be important in reducing anxiety and confusion.

Based on this research, PATH developed a series of brochures and leaflets regarding all aspects of breast cancer early detection, clinical care, and recovery.\*\* These were made available to a number of oncology hospitals and polyclinics, to the Ministry of Health, and to survivor groups. Many survivors participating in the Peer Support Volunteer Program now disseminate the brochures to newly diagnosed women and answer questions regarding their own experiences with treatment and recovery (although they are trained to refer women to their doctors to answer specific medical questions). The response among women to these brochures has been extremely positive. In addition, survivor groups in two cities (Chernihiv and Kyiv) have initiated telephone "hotlines" as a resource for breast cancer patients and their families.

### Forging Alliances with the Medical Community

A key challenge for breast cancer survivors worldwide has been to demonstrate to the medical community that their efforts will facilitate-- rather than hinder or challenge-- the work of medical providers. In many countries today, survivors and medical personnel have formed valuable partnerships in a wide range of areas, from clinical care to advocacy and fundraising. While most survivors may not be medical experts, they *are* experts in coping with the disease, and their experience and credibility must not be minimized.

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\* For more information about the Breast Cancer Peer Support Volunteer Program, contact the PATH Ukraine office at the address listed on the last page.

\*\* For a complete list of materials and information on their availability, please contact the PATH Ukraine office at the address listed on the last page.

In Ukraine, among their many efforts, survivors have sought out meetings with chief doctors and surgeons and have increasingly made themselves available to speak at professional conferences. The most noteworthy event in this regard was the participation of a panel of eight survivors who each presented their "stories" at a National Breast Cancer Conference in Kyiv for medical providers in November 1999. In describing their histories with the disease, they each made compelling pleas to the doctors present not to be afraid to discuss the diagnosis with women openly and honestly, as they, as patients, deserve to know the truth. In addition, they implied that this frankness paves the way to more constructive patient-provider relationships. This was perhaps the first time that patients were invited to participate in a medical conference in Ukraine, and for most of these women, it was the first time that they had spoken publicly about their illness. Opportunities to exchange viewpoints on this issue need to be further encouraged. In addition, medical providers can facilitate the dissemination of information about the role of survivors in supporting patients by inviting them to future meetings and further exploring how to strengthen this potential collaboration.

### Public Awareness

The very formation of survivor groups represents an important challenge to the prevailing practice of keeping the disease shrouded in secrecy—whether at the societal or at the individual level. By coming together to provide mutual support, survivors not only are able to improve their emotional and psychological well-being, which, in turn, may aid their overall recovery, but they gain confidence and courage to speak openly about their feelings, their fears, and their wishes. This often leads to a greater willingness to acknowledge beyond their immediate families that they have had the disease. While the survivor "movement" in Ukraine has just begun, one need only look to other countries to see that as survivors gain strength and confidence, they play increasingly important roles in educating the public, in general, and women at risk, in particular, about the importance of early detection. Many feel passionately that they must inform other women about the disease and how to prevent its worst consequences, and their efforts, therefore, often complement and enhance those of health providers to encourage early detection.

In Ukraine, as women become more willing to publicly acknowledge their fight with the disease, they, too, can play increasingly important roles in public education. Indeed, this process has already begun, as women in several cities have been featured in national and oblast news articles in which they have openly described their stories. (For example, articles have appeared in the Kyiv Herald [*Kyyivs'kyi Visnyk*] and the Evening News [*Vechirni Novyny*]). In some cities, poetry readings and art shows have been organized. It can be expected that in the coming years, Ukrainian breast cancer survivors will follow in the footsteps of their sisters in other countries, who have organized national events such as marches to bring attention to the disease and raise public awareness. Their courageous efforts to break the stigma that still surrounds the disease deserve encouragement and support.

### Advocacy

Although many of the survivor groups in Ukraine are new, the emergence of leadership among the survivors themselves has been noteworthy. These leaders have begun to play

essential roles in prioritizing and expanding the scope of activities that the groups undertake. This has effectively begun to push the groups beyond their primary function of providing mutual support and into the realm of outreach, advocacy, and activism. Although most of the existing survivor groups started out modestly and informally, several (most notably in Lviv, Kyiv, and Chernihiv) have now taken steps to formalize themselves by officially registering as non-governmental organizations and by seeking local sponsors. In addition, and perhaps most impressive, representatives of survivor's groups in eight oblasts have been coming together in recent months to develop a strategy for establishing a national federation of survivor groups and to participate in specific training related to grant-writing and fundraising. In May 2000, a national conference for breast cancer survivors was convened in Kyiv—the first ever in Ukraine. Over 60 Ukrainian survivors from nine oblasts attended, as did survivors from Poland, Russia, Belarus, and the US, as well as professionals dedicated to supporting them. The conference enabled attendees to exchange information on topics ranging from self-care to political advocacy to organizational development and to further learn from and strengthen ties with survivor groups from other countries.

### Conclusion

The potential for complementary efforts between medical providers and breast cancer survivors is great, especially given the strained environment in which most medical providers work due to the current economic situation in Ukraine. Survivors can play crucial roles in assisting medical providers in addressing the psychosocial and informational needs of patients, as well as increasing public awareness about the importance of early detection, which is key to reducing breast cancer mortality. Medical providers, in turn, can play pivotal roles in the growth of self-help groups—and the survivor movement, as a whole-- by referring their patients to groups or encouraging them to talk with Peer Support Volunteers visiting the wards. They also can tell other professionals about the volunteer program and groups so that they, too, will refer their patients. As has been seen in other countries, survivors, themselves, have played a critical role in bringing breast cancer out in the open, and they deserve full support and recognition for these efforts.

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**Attachment J**

**Radiotherapy Assessment and Recommendations for Ukraine**

## **Radiotherapy Assessment and Recommendations for Ukraine**

In September 1999, PATH organized a trip to Ukraine by two experts in the area of radiation therapy. Dr. Alina Popescu, a physicist from the University of Washington, visited three radiation oncology departments in the cities of Chernihiv, Kyiv, and Odesa. Dr. Karen Lindsley, a physician from the University of Washington, also visited the departments in two cities, Chernihiv and Kyiv. The goals of the trip were to:

1. Gain a better understanding of the current approaches to breast cancer radiation therapy through interviews and observations.
2. Establish how current Ukrainian radiotherapy relates to other medical disciplines associated with breast cancer treatment—surgery, chemotherapy, pathology.
3. Assess the status of current radiotherapy equipment and supplies used in the treatment of breast cancer. Calibrate Cobalt-60 machines, and understand current sources of supplies, including radionuclide source, and their adequacy.
4. Observe radiotherapy practice being carried out on patients at the PATH project sites.
5. Assess the safety and efficacy of Ukrainian radiotherapy practices and policies given the current Ukrainian medical treatment context, and also as compared to international practices.
6. Make recommendations for further technical assistance.

### **Clinical Observations in Chernihiv and Kyiv**

Both centers frequently used pre-operative breast irradiation. In Chernihiv, standard doses of pre-operative irradiation were 25 Gy in 5 fractions to the breast with opposed fields with patient lying on side, and 22 Gy in 5 fractions to the axilla with an enface field. Following mastectomy, patients then received radiation therapy to an anterior supraclavicular field (prescribed to a depth of 3 cm) and an internal mammary field (prescribed to a depth of 4 cm) to a dose of 40 Gy in 20 fractions. Breast conservation was rarely used in Chernihiv, but reportedly, its use was gradually increasing in frequency. Consideration of breast conservation was limited to small tumors measuring 2.5 cm or smaller, located in the outer quadrants. For patients undergoing breast conservation, radiation therapy was delivered to the breast post-operatively to a dose of 40 Gy in 20 fractions. In Kyiv, the fractionation of the pre-operative irradiation depended on the expected timing of the surgery and included the following schedules: (1) 13 Gy to the breast, 10 Gy to the axilla in a single fraction on day of, or one day prior to surgery; (2) 21 Gy to breast and 15-18 Gy to axilla/subclavian areas in 3 fractions; (3) 27 Gy to breast and 22.5 Gy to axillary/subclavian areas in 5 fractions. Breast conservation was limited to small T1 tumors located in the outer quadrants. In the setting of breast conservation, radiation therapy was given post-operatively using Cobalt to a dose of 40 Gy in 20 fractions to the breast and supraclavicular site. Parasternal irradiation was added in cases of medial tumors. Interestingly, however, the radiation oncologists described the use of pre-operative irradiation in the setting of breast conservation when the linear accelerator was functioning. In such cases, pre-operative irradiation was given to the tumor bed to a dose of 50 Gy in 25 fractions, with electrons, prior to the lumpectomy. This was followed post-operatively by breast irradiation. At both institutions, locally advanced tumors were treated with pre-operative irradiation in an attempt to achieve tumor shrinkage prior to mastectomy.

The pathological classification scheme as outlined in the translation of the Chernihiv protocol included categories of thyroid pathogenic form, ovarian pathogenic form, adrenal pathogenic form, and involutinal pathogenic form. However, based on our review of the pathology notes in the patients' charts and in discussion with the radiation oncologists in Chernihiv, we did not see reference to this classification system. The vast majority of tumors were classified as ductal carcinomas. It would appear then that the translated Chernihiv protocol may be outdated and no longer in use. We did receive a one-page, hand-written note from one of the radiation oncologists in Chernihiv, which apparently summarizes their treatment practices based on tumor stage. Translation of this may provide a more accurate overview of their current treatment strategies, particularly as they relate to radiation oncology.

Both centers restricted the use of breast conservation to small tumors located in the lateral quadrants. The rationale for excluding medial tumors from consideration of lumpectomy was unclear. One radiation oncologist felt it might relate to the technical difficulty of performing a cosmetically acceptable lumpectomy at this site. However, it is possible that the *perceived* high risk of internal mammary spread may be a factor. Post-operative parasternal irradiation was used routinely for medial tumors, and the presence of an intact breast adds to the complexity of achieving a uniform dose across the internal mammary nodes at depth.

### **Radiotherapy Equipment and Supplies**

In all three visited sites, the radiotherapy is performed using Cobalt-60 machines of Russian production (Agat and Rokus). The Cobalt-60 radioactive sources are produced in Russia (Siberia). In Kyiv, a betatron, producing high-energy photons and electrons, has been out of use for more than one year. After a major repair, the new machine characteristics were not measured due to the lack of a computerized water phantom. The physicists are still waiting for available funds to buy the whole measurement ensemble from Western Europe. Another linear accelerator is also purchased, but remains in storage due to lack of funding for installation and calibration.

Cobalt-60 source has a monoenergetic, low-energy (1.25 MeV) photon beam. Despite the low photon energy, Cobalt-60 can provide adequate irradiation in most cases of breast cancer, including the settings of breast conservation and mastectomy. In Ukraine, breast irradiation was often accomplished with the patient positioned on one side. This technique has the effect of reducing the total thickness of the breast and represents an ingenious adjustment to the low photon energies available in Ukraine.

All sites had ion chambers and electrometers of Russian production for output measurements. The main problem consisted in their calibration. In Chernihiv, a standard, 20-year-old cobalt source could no longer be used for calibration. The beam measurements were performed in air using the chamber with the standard cap for Cobalt-60 energy (0.5 cm). Most of the data measured in air could be converted in water (tissue), with the exception of the profile measurements where the penumbra region and beam divergence cannot be properly described from air measurements.

## Treatment Planning

The Cobalt-60 data are well known and tabulated in different publications. However, the radiation therapy physicist has to measure all of them for different field sizes and depths in water, for each particular cobalt machine. These beam characteristics may be modified from the table values by the different scattering conditions in the head of the cobalt machine, by the size and position of the source in the head. The measured data should be verified (spot checks) periodically following a quality assurance (QA) program.

In the case of Chernihiv, the patient radiation treatment planning is reduced to one point at a certain depth in the treatment volume (hand calculation). The external contour is obtained manually as well. Overall, the hot or cold spots in the treatment volume or in the normal tissues cannot be avoided in this system.

A computerized treatment-planning system of Russian production was used in the larger facilities of Kyiv and Odesa. The inhomogeneity corrections could be accounted for, and the quality of the treatment could be judged. In an example of breast therapy planning, a single, cross-sectional view was shown to us, which contained hot spots of about 25%. However, ideally, the treatment planning should include different slices from the lowest to the highest position across the breast or chest wall in order to have a three-dimensional view of the treatment volume. None of the facilities visited used wedges to improve the homogeneity of the dose distribution in the treatment volume. The use of a combination of wedged and open beams could significantly improve the uniformity in the treatment volume to less than 10%. However, the proper implementation of wedges requires a significant amount of physicist work to properly describe the wedge factors (WF) and wedge profiles at different depths in water for each particular wedge.

## Calibration of the Cobalt-60 Machines

In order to assess the status of the current radiotherapy equipment used in the treatment of breast cancer, output measurements for the Cobalt therapeutic machines were done at two sites, Chernihiv and Odesa, using the equipment from University of Washington Medical Center. We used the TG 21 protocol for calibration of the radiotherapy equipment, a polystyrene phantom, an ion chamber, and an electrometer transported from Seattle. The calibration of the ion chamber and electrometer was performed in United States at a national laboratory (University of Wisconsin-Madison).

**Table 1.** The beam output calibrations for the measured Cobalt machines (cGy/s)

Chernihiv						Odesa					
AGAT			ROKUS			AGAT1			AGAT2		
In use	Measured	% off	In use	Measured	% off	In use	Measured	% off	In use	Measured	% off
0.964	0.969	0.5	1.84	1.71	7.6	1.44	1.43	0.7	1.76	1.63	8

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As seen in Table 1 above, the differences between the measured and used beam outputs are significant for one Cobalt machine at each location.

### **Assessment of the Safety and Efficacy of Ukrainian Radiotherapy Practices and Policies**

Based on our observations collected in the short time spent at each particular site, the safety polices seem to be similar to standard radiation oncology departmental guidelines. No background radiation measurements were done. At one site, Chernihiv, there is a suspicion of a radiation leakage at one of the machines (Rokus). The source housing has apparently been reinforced in the interim.

The 8% difference in measured and used output factors, which was found for one Cobalt machine at each of the tested facilities, is of clinical significance. Factors contributing to the error in beam output measurements at the facility likely include a suboptimal QA program of the mechanical and radiation checks of the machines. The isocenter, where the beam output should be defined, was determined at the facilities using “standard cut” wooden rulers with a precision of approximately 5 mm. The lateral optical cross hairs were out of the central axis (about 1.0 to 1.5 cm at the central axis) due to a light change. Unfortunately, the machines do not have optical distance indicators (ODI) properly adjusted to show the SAD (source-to-axis distance) or SSD (source-to-skin distance).

In Chernihiv, the beam output—or better said—the Cobalt-60 activity, is calculated (hand calculations) considering the decay in time after the initial activity evaluation by the engineering group changing the cobalt sources. There are no calibrated instruments at this site to perform beam measurements periodically.

From a clinical viewpoint, the available Cobalt-60 treatment machines are adequate to provide acceptable treatment of breast cancer patients in both a breast conservation and mastectomy setting. However, treatment techniques could be further optimized, as suggested below, to improve the therapeutic ratio. The routine use of pre-operative irradiation prevents the individualization of radiation-therapy regimens based on pathologic findings. In addition, the hypofractionated regimens frequently used in the pre-operative setting are not optimal in maximizing the therapeutic ratio of efficacy over side effects. There appeared to be significant misperceptions on the applicability of breast conservation. For instance, the reluctance to perform breast conservation for small medial tumors is not justified. The risk of spread to the internal mammary lymph nodes is very low with small medial tumors when axillary lymph nodes are negative. This should obviate any concerns regarding dose inhomogeneity to the internal mammary field in the presence of an intact breast, since internal mammary lymph node irradiation is not indicated in this setting. The use of pre-operative electron irradiation to the tumor bed prior to lumpectomy is an interesting consideration as was described in Kyiv when the betatron machine was operational. In the United States, the entire breast is irradiated to approximately 45 to 50 Gy, following which, the lumpectomy site or tumor bed is boosted with electrons for an additional 10 to 15 Gy to a total of 60 Gy. The lumpectomy cavity is often defined by surgical clips left at the time of lumpectomy, which are then imaged at the time of simulation. As described at the Kyiv facility, the tumor site was treated pre-operatively with electrons to approximately 50 Gy. Following lumpectomy, the whole breast was then treated to

40 Gy. This results in a cumulative dose of 90 Gy around the lumpectomy site and may result in increased fibrosis and an overall worsening of cosmetic results. We would suggest a reduction in the pre-operative irradiation dose to the tumor bed to approximately 20–25 Gy, so that the cumulative dose following post-operative breast irradiation does not exceed 65 Gy. However, giving the “tumor bed” boost prior to lumpectomy may be reasonable in Ukraine, since placement of surgical clips at the time of lumpectomy for localization of the lumpectomy site, as well as imaging of the clips at the time of radiation treatment planning, did not appear to be feasible at the Ukrainian facilities.

Unlike facilities in the United States, the Ukrainian facilities provided inpatient rooms for patients undergoing radiation treatments, thus eliminating problems of daily transportation which otherwise would be substantial.

### **Recommendations**

From the physics point of view, radiation therapy in Ukraine could be significantly improved. Changing the technology—using linear accelerators—is not a realistic dream. However, optimizing use of currently available technology is feasible with limited spending. The following suggestions have been made by our physicist:

1. For a proper QA program, it is absolutely necessary to have a calibrated ion chamber plus electrometer and a water or solid phantom. A polystyrene phantom 25 cm x 25 cm x 25 cm costs about \$2,000. A water phantom could be made locally at each site for profiles, TPRs (tissue phantom ratios), DD (depth dose) measurements. An ion chamber plus electrometer would cost approximately \$3,500. The chamber or diode movements in water should be precisely monitored ( $\pm 1.0$  mm). It is very probable that some institutions in the United States or Canada have old water-phantom systems in good functioning state which they would consider donating for the cost of transportation. These systems include computer, programs, film dosimeter, and possibly, ion chambers.
2. A National Center for instrument calibration should be implemented at one institution (probably Kyiv), or discussions with the European Community should be carried out in order to assure a proper calibration of all instruments in Ukraine.
3. The National Center should periodically check each machine beam output and beam characteristics in Ukraine. This could be achieved using TLDs (thermoluminescent dosimeters) or calibrated instrumentation. If TLDs are used, the irradiated TLDs should be sent to the national center, which is responsible for their calibration and measurements. If an ion chamber is used, a trained physicist would take measurements at the site. Some checks of the treatment computer beam data and planning should be part of these controls, at least for a while.
4. In order to improve the dose distribution uniformity in the treatment volume, wedges could be made and used in patient treatment. Their characteristics (wedge factors and profiles versus depth) should be measured in water and introduced in the patient treatment plan.

5. A "school" of medical physicist education could be started, first for the people working in the field and afterwards, for new generations of medical physicists. A medical physics program could be started at the university as part of the physics department.
6. An organization of medical physicists should be formed in order to coordinate the efforts of the physicists from Ukraine in creating a QA program in education, safety, etc. The medical physicists should meet on a regular basis and discuss patient treatment protocols, a safety program, and a QA radiation physics program for Ukraine. Communication between all the medical physicists should be strengthened.
7. Books and other publications could be sent to Ukraine as donations from the United States or other countries. A few physicists could be sponsored to become members of different medical physicist associations from Europe or the United States. This will bring at least the benefit of receiving a medical physics journal.
8. If there were available funding to support the activity, a physicist from each of the centers could visit the radiation physics division at the University of Washington in order to gain first-hand knowledge of standard practices, protocols, and QA programs in radiation physics. He or she should spread the knowledge to other medical physicists in Ukraine.
9. The AAPM (American Association of Medical Physicists) could be contacted in order to coordinate some of its efforts toward Ukraine. This association has a program of sponsoring former socialist countries.
10. An international conference of medical physicists could be organized in Ukraine in order to bring present knowledge of cancer treatment from other countries to Ukraine. At the same time, a coordinated effort could be generated between West European countries and the United States and Canada in supporting all these new developments in Ukraine.

From a clinical point of view the following interventions could be considered:

1. Literature, including standard radiation therapy texts and review articles relating to breast cancer therapy, could be provided to the Ukrainian radiation oncologists. Translations may be required for the smaller facilities such as Chernihiv where many of the physicians are not able to understand English. However, the primary radiation oncologist in Kyiv indicated that she could read English, but had difficulty obtaining current radiation oncology textbooks. Alternatively, modern textbooks or articles written in German could be provided, since it appeared that German was a common second language. Improved access to current medical literature could be used to highlight the following: (1) the increased use of breast conservation, which should not be limited to laterally-located tumors; (2) the advantages of post-operative as opposed to pre-operative irradiation; (3) the improved therapeutic ratio gained with more conventionally fractionated radiotherapy regimens; (4) the improved dose homogeneity obtained with the use of wedges for breast irradiation; (5) specific indications for lymphatic irradiation to the axilla, supraclavicular, or internal mammary regions; (6) better patient immobilization and field matching techniques to improve consistency in patient set-ups and allow more precise matching of fields. The latter is important to prevent

the occurrence of either field overlapping—with resulting overdose, or field gaps—with resulting underdose.

2. Sponsorship of Ukrainian radiation oncologists to allow attendance at international radiation oncology meetings. The language barrier would need to be addressed, with either access to a translator or use of a common second language such as German.
3. Sponsorship of Ukrainian radiation oncologists to allow visitation to modern radiation oncology facilities either in Europe or the United States. Most of the concepts of modern breast irradiation, including treatment planning, patient immobilization, use of wedges, etc., are independent of the actual type of treatment machine. Actual participation in the treatment setups, simulations, and treatment planning sessions would serve to consolidate concepts presented in the medical literature. The Ukrainian radiation oncology physicians appeared quite open to new ideas and highly motivated to provide the best therapy for their patients. They are often in a better position than we are to determine how some of these modern techniques may be implemented at their facilities, with modifications, as necessary, based on the realistic availability of specific technologies.

**Attachment K**  
**Project Indicators Chart**

## UKRAINE BREAST CANCER ASSISTANCE PROJECT-INDICATORS

PATH Objectives	Process Indicators	Final Project Accomplishments January 1997–September 2000
A. Enhance provider knowledge and skills.	<ol style="list-style-type: none"> <li>1. Five seminars/workshops conducted; at least two dealing with treatment issues.</li> <li>2. One study tour in United States for seven clinicians conducted; one to two individual study visits.</li> <li>3. Two training modules developed.</li> <li>4. Twelve key journal articles summarized and translated.</li> <li>5. Attendance at international conferences related to breast cancer sponsored for two Ukrainian scientists/clinicians.</li> <li>6. Fifty technical-assistance visits made to project sites.</li> <li>7. Core of fifteen master trainers for training clinicians created.</li> </ol>	<ol style="list-style-type: none"> <li>1. Fifteen skills seminars/workshops conducted; six dealt with treatment issues. Two clinical symposia and one national summation conference also conducted.</li> <li>2. One study tour in United States for seven clinicians conducted; four individual study visits to U.S. supported.</li> <li>3. Six training modules and one video on clinical breast exam developed for medical providers.</li> <li>4. Twelve technical articles and/or case studies in English provided; plus one <i>Handbook on Immunocytochemistry</i> produced in Russian.</li> <li>5. Sponsored attendance by three Ukrainian clinicians at international conferences in European countries.</li> <li>6. Sixty-seven technical-assistance visits to project sites by U.S. staff and/or consultants conducted.</li> <li>7. Core of one hundred sixty-eight master trainers created.</li> </ol>
B. Improve quality and availability of equipment and supplies.	<ol style="list-style-type: none"> <li>1. Seven pieces of major equipment obtained at discounted prices.</li> <li>2. Four to five Ukrainian physicists or technologists trained in equipment maintenance and/or repair.</li> <li>3. Thirty patient courses of systemic therapeutics provided for evaluation.</li> </ol>	<ol style="list-style-type: none"> <li>1. Seven major and five minor pieces of equipment obtained at discounted prices; six major pieces and nine minor pieces of equipment donated to project sites.</li> <li>2. Radiotherapy physicist provided advice on radiation equipment maintenance. No other technologists trained.</li> <li>3. Thirty patient courses of systemic therapeutics provided for neoadjuvant chemotherapy trial.</li> </ol>

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## UKRAINE BREAST CANCER ASSISTANCE PROJECT-INDICATORS

PATH Objectives	<u>Process Indicators</u>	Final Project Accomplishments January 1997–September 2000
	<ol style="list-style-type: none"> <li>4. At least \$2,000 value of lab reagents provided for diagnosis.</li> <li>5. Local sources of prosthetics identified and/or local production established or enhanced.</li> <li>6. Twenty-one breast models for CBE training provided.</li> </ol>	<ol style="list-style-type: none"> <li>4. \$14,000 in lab reagents provided for diagnosis (one-third obtained through donations).</li> <li>5. Local source of prosthetics identified, but assistance with production or distribution not supported.</li> <li>6. Twenty-nine breast models for CBE training provided.</li> </ol>
C. Increase patient and public understanding of breast cancer.	<ol style="list-style-type: none"> <li>1. Involve patients and providers at each site in the design, pretesting, and revision of materials.</li> <li>2. Foster collaboration between dispenser and Health Education Center staff in the three sites.</li> </ol> <p style="text-align: center;"><i>Patient Education</i></p> <ol style="list-style-type: none"> <li>3. Conduct a minimum of six focus-group discussions (FGDs) to gather qualitative data regarding women's knowledge, attitudes, and practices regarding breast cancer.</li> <li>4. Conduct a minimum of six FGDs to pretest patient informational/educational materials.</li> <li>5. Develop a minimum of six informational/educational materials for patients.</li> <li>6. Dub/adapt at least one video.</li> </ol>	<ol style="list-style-type: none"> <li>1. Patients and medical providers at each site reviewed all materials published.</li> <li>2. Collaboration strong in Chernihiv and encouraging in Kyiv (via Kyiv City Oncology Center); contact initiated in Odesa.</li> <li>3. Conducted ten FGDs with women and nine in depth interviews with medical providers using services of Ukrainian Surveys and Market Research.</li> <li>4. Conducted ten FGDs to pretest patient materials.</li> <li>5. Developed eleven different pieces: three brochures on diagnosis and treatment, three informational flyers, three brochures on self-care after treatment, one brochure for the family, and one relaxation tape.</li> <li>6. Adapted one video on breast self-exam for women.</li> </ol>

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## UKRAINE BREAST CANCER ASSISTANCE PROJECT-INDICATORS

PATH Objectives	Process Indicators	Final Project Accomplishments January 1997-September 2000
	<p><b><i>Public Awareness Campaigns</i></b></p> <p>7. Broadcast a minimum of five radio ads in the pilot-screening site.</p> <p>8. Publish at least one newspaper article in two project sites to increase awareness of breast cancer and local resources.</p> <p>9. Develop a minimum of one poster and two pamphlets.</p> <p>10. Develop a national IEC strategy.</p>	<p>7. Produced three radio/TV spots, which were broadcast in Chernihiv City and raion on a continual basis once screening program initiated in July 1998.</p> <p>8. Provided information for twenty-two publicity pieces (newspaper and magazine articles, TV interviews) to increase awareness, particularly in Chernihiv and Kyiv.</p> <p>9. Developed six different pieces: one poster, one informational flyer, and four brochures.</p> <p>10. Draft national IEC strategy shared with MOH but not finalized.</p>
D. Strengthen health infrastructure.	<p>1. Figures on number of women screened by mammography, number, and stage of cancers detected, and other data essential for program monitoring available in database format in all three project sites.</p> <p>2. System for disseminating key information to clinicians established.</p>	<p>1. Information in <i>National Cancer Registry</i> (key source of data for monitoring) now more reliable following PATH's technical assistance. Database developed in radiology unit in Chernihiv oblast oncology center to tract mammography patients.</p> <p>2. System established, however, e-mail not available widely enough. Distribution of paper copies of key information most effective as part of skills training, symposia, and at national summation conference.</p>
E. Refine policies and practices.	<p>1. Consensus report on clinical practices produced.</p> <p>2. Two to three issue summaries prepared.</p>	<p>1. Produced report "Early Detection of Breast Cancer in Ukraine: Strategies and Lessons Learned for Future Planning."</p> <p>2. Three issues of summaries prepared and distributed.</p>

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## UKRAINE BREAST CANCER ASSISTANCE PROJECT-INDICATORS

PATH Objectives	<u>Process Indicators</u>	Final Project Accomplishments January 1997–September 2000
	3. PATH participation in at least four MOH meetings on policy issues related to breast cancer.	3. Participated in eight MOH meetings on policy issues.
F. Beneficiaries of project-related services.	1. Number of women screened by mammography in project sites. 2. Number of women undergoing diagnostic mammography. 3. Number of Chernobyl-affected women screened or diagnosed in project sites. 4. Number of printed materials distributed.	1. Chernihiv – 4,804; Odesa – 1,926; UCDBD – 0. 2. Chernihiv – 6,594; Odesa – 2,217; UCDBD – 4,310. 3. Chernihiv – 635; Odesa – 16; UCDBD – N/A. 4. Through a variety of channels, 317,200 individual pieces were distributed throughout country.

## UKRAINE BREAST CANCER ASSISTANCE PROJECT-INDICATORS

PATH Objectives	Impact Indicators	Final Project Accomplishments January 1997 – September 2000
<p>A. Increase early detection in more treatable stages.</p>	<ol style="list-style-type: none"> <li>1. Decrease in percentage of new cases with Late Stage at diagnosis (III, IV) after CBE training and public-awareness campaign complete.*</li>   <li>2. Decrease in rate of mortality less than one year after diagnosis.*</li>   <li>3. Increase in percentage of new cases with Stage I at diagnosis in mammography pilot-screening group.*</li>   <li>4. At least 50% coverage of women in the designated target group who have had screening mammogram in past two years.+</li> </ol>	<ol style="list-style-type: none"> <li>1. From 1996 through 1999 the percentage of new cases that were late Stage (III, IV) declined by 24% (from 47% to 36%). The absolute number of very late stage cases (Stage IV) declined by 49%, with most of the drop occurring in 1999.</li>   <li>2. Data on cases diagnosed in 1999 will not be available until 2001. Since about two-thirds of such deaths occur among women initially diagnosed at Stage IV (which dropped dramatically), one might project (but not yet show) that the early mortality might also have dropped by about 32%.</li>   <li>3. In Chernihiv City, there was a 16% increase in Stage I detection (from 18% in 1997 to 21% in 1999), but no real change in Chernihiv raion where mammography uptake was low. There was an 84% increase (from 9% in 1996 to 16% in 1999) in Chernihiv oblast overall.</li>   <li>4. In Chernihiv raion the target of 50% coverage by mammography was not achieved. Primary users of screening mammography were from Chernihiv City. However, nearly 90% of eligible women in Chernihiv raion were screened by CBE in 1999.</li> </ol>
<p>B. Improve quality of screening and diagnostic care.</p>	<ol style="list-style-type: none"> <li>1. Achievement of passing results on “phantom” testing of mammography in all three sites at least 80% of the times testing is carried out by the final six months of the project.+</li> </ol>	<ol style="list-style-type: none"> <li>1. Results of “phantom” testing were not recorded systematically by the sites, but mammography at all three sites was observed by outside experts to have improved significantly in quality of image.</li> </ol>

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## UKRAINE BREAST CANCER ASSISTANCE PROJECT-INDICATORS

PATH Objectives	Impact Indicators	Final Project Accomplishments January 1997 – September 2000
	<p>2. Reduction in percentage of non-diagnostic (unusable) fine-needle or core-needle biopsies.*</p>	<p>2. Expected improvement was not seen, in part because of wide range of staff involved in taking biopsies. Pathologist in Chernihiv noted significant improvement in quality of biopsies among the specific surgeons trained in the project.</p>
<p>C. Increase psychosocial support and enhance patient well being.</p>	<p>1. Increase in the proportion of clinicians who rate psychosocial support as an important aspect of care and can name several key messages from their counseling and communication training.+</p> <p>2. Increase in the proportion of patients who know basic facts about self-care.+</p>	<p>1. In the follow-up survey, 72% of oncology doctors and nurses reported always or mostly encouraging their patients to talk about their fears, compared to 38% during the baseline survey. Of particular interest is the fact that 62% believe survivors should be trained to give support to patients.</p> <p>2. In informal survey at end of project, patients reported that the materials gave practical, helpful advice. Many observers reported marked increases in patient/survivor (and provider) knowledge, especially on lymphedema, primarily as a result of the print materials and the interactions with other survivors.</p>

\*Reported semi-annually.

+Reported at end of project.

Attachment K/RDRP15601

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