

**UKRAINE BREAST CANCER SUPPORT:
PARTICIPATORY EVALUATION OF
USAID TECHNICAL ASSISTANCE**

**Provided through
THE UKRAINE BREAST CANCER ASSISTANCE PROJECT**

Implemented by the Program for Appropriate Technology in Health (PATH)

and

THE BREAST HEALTH INITIATIVE

Implemented by the American International Health Alliance (AIHA)

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ACRONYMS AND FOREIGN TERMS

AIHA	American International Health Alliance
BSE	Breast self-examination
CBE	Clinical breast examination
CEE	Central and Eastern Europe
COOC	Chernihiv Oblast Oncological Center
CQI	Continuous quality improvement
DCIS	Ductal carcinoma in situ
dispanser	Oncological center
E&E	Bureau for Europe and Eurasia
EEST	Office of Environment, Energy and Social Transition
ER	Estrogen receptor
FAP	Feldsher-akusherskii punkt (feldsher-midwife point, or post)
feldsher	Physician assistant, medic
FNA	Fine needle aspiration
FY	Fiscal year
GE	General Electric
HIV	Human immunodeficiency virus
HRHA	Health Reform and Humanitarian Assistance
ICC	Immunocytochemistry
IEC	Information, education and communication
KCOOC	Kyiv City Oncological Center
MEDS	Monitoring, Evaluation and Design Support
MOH	Ministry of Health
MRI	Magnetic resonance imaging
NGO	Nongovernmental organization
NIS	New Independent States
oblast	Provincial administrative unit, region
OOC	Odesa Oblast Oncological Center
PATH	Program for Appropriate Technology in Health
PHC	Primary health care
PR	Progesterone receptor
raion	District administrative unit
rak	Cancer
STD	Sexually transmitted disease
TNM	International standard to describe the extent of the primary tumor, a description of the lymph node involvement, and the presence or absence of distal metastases
UCDTBD	Ukrainian Center for the Diagnosis and Treatment of Breast Disease (in the Ukrainian Research Institute of Oncology and Radiology in Kyiv)
USAID	United States Agency for International Development
WWC	Women's wellness center

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EXECUTIVE SUMMARY

Health care providers in Ukraine, assisted by the United States Agency for International Development (USAID), have embarked on a pioneering effort aimed at improving the early detection and treatment of breast cancer. In Ukraine, as in Western countries before the advent of mammography and many other financially constrained countries still today, breast cancer control has relied almost exclusively on doctors determining by palpation whether a breast lump might be cancerous and then proceeding typically to perform radical mastectomies—usually at a late stage of cancer when long-term survival chances are almost nil. The work described in this evaluation represents a major leap forward for the women of Ukraine and describes a model of cancer control that may assist other countries ready to reduce unnecessary premature deaths from breast cancer among their women.

A. BACKGROUND

Breast cancer is the most common cancer among women in Ukraine. Furthermore, both the incidence of new cases and breast cancer mortality have increased dramatically in Ukraine in recent years. In addition, it is anticipated that breast cancer may become even more widespread during the first decades of the 21st century as a result of the Chernobyl nuclear power plant disaster in 1986.

The U.S. government remains concerned about consequences of the radioactive fallout after the explosion at the Chernobyl atomic reactor (Chernobyl disaster).¹ In 1996, the U.S. Congress established an earmark to provide funding through USAID “to screen, diagnose, and treat victims of breast cancer associated with the 1986 incident at the Chernobyl reactor in Ukraine.”

B. USAID SUPPORT

USAID subsequently developed two activities aimed at supporting breast cancer control in Ukraine. The overarching goal is to increase detection of breast cancer in the early stages—when the chance for a cure is the best. An important additional goal is to introduce approaches to breast cancer treatment commonly available in the international community. Budgets of the two activities total \$6.3 million. Both began implementation in 1997. USAID support is scheduled to end in 2000.

The **Breast Health Initiative** was launched in 1997 to add selected breast cancer control activities to the services of hospitals already participating in the ongoing Medical Partnership Program (CA EURO-0037-A-00-4016-00) of the American International Health Alliance (AIHA). The initiative has established breast health centers or

¹ Ukraine, a country of 50 million, became independent in 1991 following the dissolution of the former Soviet Union, under which the Chernobyl atomic reactor was built.

components within women's wellness centers in three hospitals in Ukraine (in Kyiv, Odesa, and Lviv). The objective of the Breast Health Initiative is to develop comfortable and easily accessible outpatient centers that provide breast cancer screening and diagnosis, including mammography, and educational materials related to breast cancer risk factors, early detection, and treatment. The initiative has a budget of \$2.5 million; funding is expected to extend through summer 2000. (There is no fixed completion date.)

The **Ukraine Breast Cancer Assistance Project** was designed to offer a comprehensive approach to improving breast cancer control in Ukraine. Its goal is to improve access to and the quality of breast cancer screening, diagnosis, and treatment among women in Ukraine, with an emphasis on those exposed to radiation from Chernobyl. This three-year activity (CA EE-A-00-97-00003-00) was authorized in December 1996, with a budget of \$3.8 million, and has been extended through September 30, 2000, at no additional cost. It is being implemented by the Program for Appropriate Technology in Health (PATH).

C. PURPOSE OF THE EVALUATION

The goal of this evaluation was to assess comprehensively USAID contributions to improving breast cancer management in Ukraine and to do so in a way that would contribute to building ownership and institutionalizing achievements to date within Ukrainian personnel and organizations. Priority was to be on sustainability and the future. The two activities and approaches were not to be evaluated in comparison with each another. Specific objectives were to

- identify results achieved in the breast cancer field through USAID, PATH, and AIHA;
- identify problems and constraints to achievement of the initial objectives and to further expansion by the host country;
- identify follow-up actions to be undertaken by the Ministry of Health and for national sustainability of the changes developed and tested in pilot sites;
- recommend possible breast cancer interventions to be pursued by USAID within the women's/primary health care context;
- document the results to date (including lessons learned) and impacts according to objectives of both programs, as well as in relation to applicable goals under USAID/Kyiv Strategic Objective 3.2 (improved health promotion and increased access to quality health care); and
- conduct the evaluation using participatory process (including provision of training for Ukrainian participants).

D. METHODOLOGY

A participatory evaluation was conducted during a 3–week period in May 2000, by a U.S.–Ukrainian multidisciplinary team. The process began with a stakeholders meeting followed by training of Ukrainian participants in evaluation and interviewing methodology. Data gathering methods included document analysis, field visits to Odesa and Chernihiv, interviewing of key personnel, conduct of group interviews, observation, and conference participation (see annex A).

E. MAJOR CONCLUSIONS

Achievements

A very successful start has been made and a foundation laid for making the transition for breast cancer control strategies in Ukraine to employ newer international approaches to care that emphasize early detection, more effective treatment, and patient (citizen) empowerment. In the four regions (oblasts) where PATH and AIHA have provided training, equipment, and supplies, important advances have been made along the whole cancer control continuum, from public education and screening through diagnosis and treatment, including patient education and psychosocial support. System changes have been made, especially in the four USAID–assisted oblasts. Importantly, individual women are already benefiting from improved service standards, although population-based screening was too limited and it is too soon to see statistically significant increases in breast cancer survival rates. The breast cancer survivor groups and movement for which PATH has acted as a catalyst provide patient education and support and are potentially important contributions to women’s empowerment and the growth of civil society in Ukraine.

Sustainability

The future is uncertain. On the one hand, sustaining the achievements will require funding that the Ukrainian participating institutions do not have (e.g., for supplies and maintenance). On the other hand, desire and potential to sustain the advances achieved is strong among the Ukrainian institutions and medical personnel trained and supported by PATH and AIHA. There have been attitude changes, increases in knowledge and skills, improved standards of care, and growing patient–citizen empowerment, which are advances not likely to be reversed. The breast cancer survivors’ movement is an additional force for sustaining achievements. The sustainability of all improvements and innovations in breast cancer management would be significantly enhanced if there were major health sector reforms—especially financial reforms.

Extending the Model Nationally

Beyond the four oblasts that were the focus of USAID support, considerable information sharing has taken place through conferences, training, and publications. However, given the short timeframe and limited budget, it was neither a goal nor was it possible to

introduce all the advances in the other 21 oblasts. The government has started to transfer experience through issuing clinical guidelines and recommendations on certain issues, but old practices may remain quite firmly in place in most other oblasts.

Upholding Quality

Additional mammography machines are being imported into Ukraine, outside the USAID-supported activities, by various governmental and private facilities. Without national criteria for quality (i.e., accreditation standards), which have been introduced by the PATH and AIHA initiatives, new machines may be introduced without quality controls and without appropriate utilization guidelines. If free-standing mammography centers are established and not linked to cancer treatment centers, women with breast problems run the risk of being left to their own devices to seek additional evaluation and treatment.

F. MAJOR RECOMMENDATIONS

1. During the remaining months of the current USAID support, PATH and AIHA should initiate a process with their participating partners and the Ministry of Health (MOH) to firmly establish minimum criteria for centers wishing to introduce modern mammography in their community. At a minimum, this should include: (a) criteria for accreditation of mammography centers (accreditation standards for screening and diagnostic mammography) and (b) availability of referral to evaluation and treatment resources for women found to have suspicious or abnormal mammograms. Screening should not be carried out without referral for treatment being in place.
2. PATH and AIHA should both be preparing final reports of this activity. The goal of the narrative section should be to document the lessons learned in a way that is useful both for sustaining and extending accomplishments in Ukraine and for sharing with other countries.
3. USAID and AIHA should continue to support selected components of breast cancer care within their primary health care and women's/reproductive health frameworks. The goal of USAID/Kyiv's Health Strategy is to assist Ukraine in reforming primary health care and improving the capacity of health practitioners to effectively and efficiently provide community-based health services. Well-organized cancer screening is an important component of primary health care based on prevention, early detection, and appropriate basic care. Psychosocial support at the community level is an important dimension in primary health care. As such, breast cancer activities 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.

I. MAJOR CONCLUSIONS AND RECOMMENDATIONS

A. SUMMARY

Benefiting from funding provided by the United States Agency for International Development (USAID), a solid foundation has been laid for modernizing breast cancer control in Ukraine. As a result, both the stigma of diagnosis and the fear of death associated with breast cancer have been reduced, and ultimately, survival rates will improve as a result of effective treatment of earlier stage disease. Assisted by the Program for Appropriate Technology in Health (PATH), the American International Health Alliance (AIHA), and their Ukrainian partners, the Ukrainian public in the four USAID–assisted oblasts (regions) has been exposed to a campaign to increase awareness of the importance of early detection of breast cancer—that it is most curable in these early stages. In addition, health care professionals have been exposed to major advances in breast cancer control strategies. These advances include

- updated breast cancer curricula introduced in schools of nursing and medicine;
- education and training of health care providers, who in general are self-motivated and participate actively in a wide dialogue with their peers and with the public about breast cancer;
- technical advances in the capacity to evaluate and diagnose breast cancer;
- opportunities to develop multidisciplinary teams both in the evaluation of breast disease and in the treatment of breast cancer; and
- improved psychosocial support services for breast cancer patients and survivors.

In addition, technical capacity and infrastructure strengthening have occurred through the

- provision of equipment and supplies, especially mammography equipment (including equipment for developing films) and ultrasound and pathology supplies (including microscopes and for immunocytochemistry) and
- improvements in cancer registries (both regional and national) and the addition of information systems in key locations.

B. BREAST CANCER CONTROL CONTINUUM

A Comprehensive Approach to Breast Cancer

An important lesson learned is that a comprehensive approach to breast cancer control will have far more impact than a piecemeal approach concentrating on only one component. In addition, screening, whether through mammography or clinical breast examination (CBE), must be linked to multidisciplinary evaluation and treatment services. Early detection of breast cancer without effective therapy is insufficient to improve breast cancer mortality. Moreover, it would be unethical to introduce improvements in access to screening services aimed at the early detection of breast cancer without also assuring that women have access to effective treatment services. However, advanced treatment without early detection is insufficient to reduce breast cancer mortality.

Recommendation: Efforts to improve breast cancer control—whether by international donor, the Ministry of Health (MOH), or oblast/region—should include approaches to achieve comprehensive change—in attitudes, knowledge, and procedures—along the whole continuum of public awareness, provider and patient education, improved diagnosis and treatment, and psychosocial support.

Public Awareness

At both the local and national levels, public awareness of the importance of early detection of breast cancer and knowledge of where to go for screening, evaluation, and care has been increased. Successes at the local level are indicated by both data and the perception that there is increased demand for services (both screening and evaluation of problems). Increased media coverage is not only a means to increase awareness but also evidence of emphasis being placed on early detection. Recently formed breast cancer survivor groups are also contributing to public awareness.

Recommendation: The MOH, partner institutions, and survivor groups should continue efforts to build public awareness on the value of early detection. The public education efforts should also include efforts to explain established risk factors for breast cancer and to encourage those women who are at increased risk (owing to their exposure to radiation from the Chernobyl accident) to be evaluated.

Chernobyl At-Risk Women

Neither PATH nor AIHA has directed efforts specifically to individual women exposed to radiation from Chernobyl. However, PATH focused on the Chernihiv oblast, where many people exposed to Chernobyl radiation are living, and on Kyiv oblast, which also has a large number of Chernobyl victims relocated from the restricted, most contaminated zone. Thus, as a result, services in Chernihiv and Kyiv are more ready to serve female Chernobyl victims who develop breast disease.

Recommendation: Girls and young women exposed to excess radiation doses at the time of the Chernobyl accident are at increased risk for developing breast cancer and should be advised to seek screening. Public education campaigns that are aimed at all women should also educate women at increased risk, particularly women with radiation exposure from Chernobyl, and should advise them to seek screening for breast cancer.

Patient Education and Empowerment

Patients in the partner hospitals are generally better informed and more knowledgeable about breast cancer than previously and more so than in other hospitals today. This is uneven among the partner hospitals, but there is some evidence in all partner hospitals of this progress. In the most progressive facilities, patients are—and feel—much more involved in the diagnosis and treatment decision-making process than in the past. A major contribution has been the patient education materials prepared by PATH and AIHA that are widely available and used in all the participating facilities as well as many others. Informed consent, an innovation in breast cancer care in Ukraine, has been introduced in two sites. Women, especially in the AIHA-supported women’s wellness centers, are encouraged to regard breast health as part of their overall health as a woman.

Decreased Fear of Breast Cancer

The education of both patients and providers is making important contributions toward reducing the level of fear among women, which contributes to improved outcomes. Women who are less fearful are more willing to go for screening and to return for follow up or treatment. Doctors who are more comfortable talking with patients about cancer are helping to reduce fear. Survivor groups who provide inhospital information, counseling, and psychological support to breast cancer patients are a major force in reducing fear and building coping skills.

Professional Education

A major effort in training and educational activities has resulted in substantial improvement of knowledge, attitudes, and skills of physicians, nurses, and other providers involved in breast cancer, especially in the USAID-assisted oblasts. In many cases, passive knowledge was transformed into practical ability and hands-on skills. Many Ukrainian doctors had read about various international advances but had not had the opportunity to apply them to their work. PATH and AIHA gave opportunities to acquire first-hand knowledge and develop hands-on competence and proficiency. Training and educational activities have included undergraduate, graduate, and continuing medical education; inservice training; peer review and peer collaboration; study tours to the United States; and establishment of electronic mail and Internet communication with U.S. partners. As a result, professionals involved in breast care in the four USAID-assisted oblasts have significantly increased their knowledge and skills regarding clinical breast examination (CBE), natural history of breast disease, early detection, primary and extended diagnostic technique, new treatment approaches, and

psychosocial support. There have been equally important changes in attitudes and mindsets as needed to back away from radical mastectomy (removal of breast, breast muscles, and lymph nodes) as a standard treatment in favor of more breast-conserving approaches. This new knowledge is permitting a higher quality of patient care and is starting to lay the foundation for sustainability. Many of the providers feel ownership of the new knowledge; evidence of this new knowledge has begun to appear in professional articles and presentations in public meetings.

Recommendations

- The breast cancer curriculum for medical students needs to be strengthened at all levels and made consistent with international standards. Without this, there can be no sustained impact. Communication with peers in the United States and Eastern Europe, initiated and facilitated by PATH and AIHA, must continue in order to keep the Ukrainian leaders in this transformation motivated and abreast of new developments.
- The regular, inservice refresher training for all specialists (doctors, radiologists, nurses, technicians, feldshers) should be based on, and thus consistent with, the strengthened curricula used for basic training of doctors and nurses.

Screening by Clinical Breast Examination (CBE)

Given the cost of both the purchase and maintenance of mammography equipment (which will remain beyond the means of Ukraine for the foreseeable future), CBE will be very important for screening and early detection of all but the smallest, nonpalpable cancers (stage II and above, plus some stage I). Important measures have been taken to improve the effectiveness of CBE. In the four oblasts supported by PATH and AIHA, a model for low-cost breast cancer screening through CBE has been established that includes public awareness, client counseling, and provider competence at all levels. PATH developed a comprehensive CBE curriculum with a slide set; CBE has now been established in nursing curricula and representatives of all 27 basic oblast nursing schools in Ukraine have been trained in CBE. This will help spread the model to other nursing schools over time. CBE has been included to a lesser extent in medical schools.

Recommendations

- CBE performed correctly should be emphasized as an essential component of the complete physical examination of women over 18 and as critical to a comprehensive approach to early detection of breast cancer, which includes physical examination and breast imaging (mammography and ultrasound) for the evaluation of palpable abnormalities.
- MOH and regional health authorities should continue public awareness campaigns and should hold doctors and other health care providers responsible for correctly performing CBE as a standard part of the annual

physical examination for all women over age 18. Provider competence in CBE should be maintained where it has been established and should be established elsewhere.

- Efforts should continue to institutionalize CBE in the medical school curricula.
- The new CBE curriculum adopted by nursing schools should be used nationally for inservice refresher training of nurses.

Screening and Diagnostic Mammography

The quality of all mammography has improved significantly through the provision of new state-of-the-art mammography and sonography equipment, training, and emphasis on proper patient positioning, optimal use of equipment and supplies, correct reading of mammograms, and quality control. Screening mammography is now accessible to women in the PATH- and AIHA-assisted facilities and is performed at an appropriately competent level of quality. As a result, these facilities are for the first time detecting nonpalpable small breast cancers. The foundation for improving breast cancer survival through early detection has been established, but the cost of expansion and sustainability is a major issue. The importance of screening has entered the mindset of many healthy women in program communities and increased numbers of women both with symptoms and without symptoms coming to a mammography facility for screening and diagnosis. With support from PATH and AIHA, programs in screening mammography have been developed as model programs that are available for adoption in other areas. There is mounting interest on the part of other public hospitals and also private facilities to acquire mammography machines and provide mammography services. (There are reportedly already 10 additional mammography machines [General Electric] recently brought into Ukraine; 6 were purchased by oblast or private facilities and the other 4 were on speculation.)

Recommendation: The MOH should recognize the USAID/PATH/AIHA-assisted sites as pilot sites and resource centers in a national approach to upgrade mammography facilities throughout Ukraine. MOH should work together with these sites to further develop them as Centers of Excellence in mammography, and with the Ukraine Association of Radiology for setting standards in mammography quality. At a minimum, this should include criteria for accreditation of mammography centers (accreditation standards for screening and diagnostic mammography), a referral system in place for women with suspicious or abnormal mammograms to have further evaluation and treatment for both benign and malignant breast disease, and a database that describes imaging and clinical outcomes for all screening and diagnostic mammograms obtained at the facility. Screening should not be carried out without systems for referral being in place.

Clinical Evaluation and Diagnosis

Increased diagnostic accuracy is resulting in more appropriate management of both breast cancer and benign breast disease. For breast cancer, there is increasing use of breast-conserving treatment. For benign breast disease, there is less surgery and more follow up. Increased diagnostic accuracy is due to the improved quality of diagnostic mammography, ultrasound, and fine needle aspiration; increasing recognition and acceptance of the importance of quality control (including adoption of American College of Radiology standards); and increased participation of the pathologist as a member of the team.

- **Diagnostic imaging:** The improved quality of breast imaging with mammography and ultrasound results has led to improved diagnostic accuracy for both malignant and benign breast disease. This is essential in establishing criteria for following mammographic change likely to be benign, rather than assuming that all mammographic abnormalities are either cancerous or precancerous and treating them as such.
- **Immunocytochemistry (ICC):** The introduction of ICC for breast tumor markers, specifically for determining estrogen receptor (ER) status, is an important advance for both prognosis and treatment planning. Use of ICC for determining ER status is part of international treatment guidelines and establishes the potential for more appropriate use of anti-estrogen therapy (tamoxifen) in treatment. PATH introduced ICC in Odesa, Kyiv, Chernihiv, and Lviv, and through conferences and distribution of manuals to other oblasts, which are now familiar with the approach. Sustainability is questionable, however, due to costs.
- **Team approach:** Program activities have resulted in strong diagnostic teams (surgeon, mammographer, ultrasonographer, and pathologist) in most participating sites. The team approach contributes to both improved diagnosis and treatment.

Recommendations

- New mammography centers should be encouraged to develop multidisciplinary approaches to the evaluation and diagnosis of breast disease. The diagnostic team should include surgeons, radiologists (both mammography and ultrasound), and pathologists.
- The MOH should consider developing experienced pathology centers as both reference laboratories and resource centers for pathology in general as well as for special diagnostic studies, such as immunocytochemistry. (Consider the Kyiv City Oncological Center as a possible site for beginning the process for thinking about a reference laboratory and considering procedures, standards, and accreditation requirements.)

Treatment Strategies

Improvements in breast cancer mortality require both advances in early detection and effective treatment of early stage disease. One marker of more effective therapy is the appearance of breast-conserving treatment for small breast cancers. Implementing partners have spurred a transition from old-style radical mastectomy (removal of breast, breast muscles, and lymph nodes) to breast-conserving technique (lumpectomy or quadrantectomy) in early stage breast cancer.

- **Early stage disease:** In PATH focal sites (Odesa and Chernihiv), increased numbers of cases (10–20 percent) are being treated with breast conservation. The increased use of breast-conserving procedures reflects both the detection of earlier stage disease and the willingness of surgeons to perform breast-conserving surgery on stage I cancers.
- **Advanced stage disease:** Neoadjuvant chemotherapy (chemotherapy administered before surgery) has been introduced and offers the possibility of breast-conserving surgery for stage II breast cancers and more effective palliation for stage III cancers.

Recommendations

- Breast cancer treatment should be monitored by the regional and national cancer registries. (Accurate recording of diagnosis, stage, and treatment is the only way to monitor changes in treatment patterns and ultimately, changes in survival associated with the effective treatment of early-stage disease.)
- Professional education initiatives should establish that modern approaches to breast cancer treatment require a multidisciplinary approach, which involves each of the treating specialties in surgery, radiation therapy, and chemotherapy.

Patient Counseling and Psychosocial Support

The new emphasis in partner institutions on patient education, counseling, psychosocial support, and involving patients in treatment decision-making is an important advance in cancer care. The challenge is to have this adopted beyond the four USAID–assisted oblasts. PATH has begun this expansion process by holding two national symposia on patient education and psychosocial support and AIHA has started a breast health community outreach program, but much more will need to be done before these major changes in new attitudes and procedures are adopted in all oblasts. The large number of detailed culturally appropriate educational materials developed by PATH and AIHA is a major contribution.

Recommendations

- The breast cancer curricula should continue to include emphasis on psychosocial aspects of breast cancer care.
- Standards for Centers of Excellence should include not only standards for technology but also for patient education and psychosocial support.
- The educational materials should be shared with other countries.

Breast Cancer Survivors' Movement

An important new phenomenon related to the recent emphases on public awareness, patient education, and psychosocial support are breast cancer survivor groups, coming together with PATH assistance. Now registering as nongovernmental organizations (NGOs) and considering a national coalition, these local groups provide mutual support and practical and coping assistance to women newly hospitalized for breast cancer. They will almost certainly be a primary force in advocacy for sustaining current improvements in breast cancer care and for citizen engagement in their own well-being.

Recommendation: MOH and breast cancer professionals should recognize these groups as partners in breast cancer program and policy development and continue to involve them as PATH did in its November 1999 summation conference.

Sustainability

The sustainability of the innovations introduced through USAID support is a serious issue. The three-year period of USAID support was too short a time to modernize breast cancer control in a financially constrained country and achieve statistically significant reduction in breast cancer morbidity and mortality. The new ways of thinking, new attitudes, and innovative practices are likely to endure in the institutions where they have been established. At the same time, the Ukrainian partner institutions are concerned about how to finance recurrent costs, such as mammography films and solutions, equipment maintenance, reagents, and ICC test kits after USAID support ends.²

Recommendations

- USAID should continue to support selected components of breast cancer care within its primary health care and women's/reproductive health frameworks.
- USAID, or another donor, should consider assisting the Ukraine health sector in structural reform.

² USAID itself acknowledges that even five years is too short for major change to be achieved. In the United States, it took more than 50 years for all the advances in breast cancer that are now being introduced in Ukraine to produce the statistically significant downturn in mortality that began to be documented in the late 1980's.

- The Ukrainian government, in view of the increasing privatization and modernization of health care in Ukraine (e.g., magnetic resonance imaging [MRI], open heart surgery), should recognize breast cancer control as a high priority for Ukrainian women and enable the MOH to take leadership and play a convening role in establishing standards.

A Model for Other Health Care Efforts

The improvements in breast cancer control that have resulted from the PATH and AIHA initiatives are models of how other important health care problems can be addressed. Educating the public, involving both professionals and the public in a dialogue about how to improve outcomes, investing in the education and training of health care professionals, establishing quality standards for patient care and for procedures, and encouraging interdisciplinary involvement in both patient care and in the development of clinical programs—all have resulted in improved professional competence and patient experiences in participating sites and will ultimately result in a decrease in breast cancer mortality.

USAID Support

USAID and its implementing partners, PATH and AIHA, have made important contributions toward improving breast cancer control in Ukraine through the transfer of knowledge, skills, and technology, especially in the four regions (Kyiv, Odesa, Chernihiv, and Lviv) where they have been working. In addition to improving cancer control strategies, these efforts have also resulted in a substantial difference in the individual experience of women served in the partner sites.

Ukraine Breast Cancer Assistance Project (PATH)

PATH has clearly met its original objectives (see section V below). Especially in the regions where PATH has worked, and nationally to a more limited extent, PATH has improved breast cancer screening, diagnosis, treatment, and access to services. PATH has focused on cost-effective screening and provision of services within existing resource constraints. Two major results of PATH support are the promotion and training of CBE for nationwide use and support to breast cancer survivor groups and a national effort toward a self-help movement. Both of these accomplishments are low cost and likely to be sustained.

Breast Health Initiative (AIHA)

AIHA has met the overall objective of its Breast Health Initiative, namely “to develop comfortable and easily accessible outpatient centers that provide breast cancer screening...and a full range of educational materials related to breast cancer prevention and treatment.” Its three women’s wellness centers present an attractive model for comprehensive women-centered care and counseling, including birth control, nutrition education, smoking cessation, and modern elements of perinatal care (e.g., Lamaze and rooming-in). AIHA’s stated objectives (see section VI below) are more specific than

those of PATH and could not be fully assessed during the time allotted for this evaluation.

Recommendation: Both PATH and AIHA should document their successes, lessons learned, issues, and remaining challenges in ways that will promote sustainability of their achievements in Ukraine and provide guidance to similar efforts in other countries.

The Ukrainian Counterpart Organizations

A major determinant of overall success was the level of cooperation, interest, and enthusiasm on the part of individuals within the Ukrainian partner organizations. A lesson learned is that to engender the maximum level of cooperation and interest, Ukrainian participants at all levels need to be more fully briefed about the activity purpose, progress to date, and allocation of resources.

Recommendation: USAID and its implementing agencies should keep the Ukrainian participants at all levels fully briefed about activity purposes, progress to date, and allocation of resources. This should be done at the beginning and periodically throughout the implementation cycle. There is a need to establish greater networking among and between partner organizations.

The Dilemma of Refurbished Equipment

PATH purchased and provided three General Electric mammography machines for its collaborating facilities: one new machine and two refurbished. One of the refurbished machines (provided to Chernihiv) was never properly refurbished and remained malfunctioning and a source of frustration during most of the PATH project. (This machine has now been fixed after a considerable investment of effort by Chernihiv and PATH personnel.) Refurbished equipment offers distinct cost-savings advantages, but competent technical support must be readily available. The question is not just obtaining refurbished versus new equipment; crucial also are the quality of the vendor, the warranty, and provisions for servicing.

Recommendation: USAID, PATH, and the MOH should convene a task force (perhaps in conjunction with recommendations under patient education and empowerment above) to ascertain that qualified technicians will dependably provide servicing on all General Electric mammography machines in Ukraine. The MOH, in partnership with the private sector, should develop for adoption a law that requires imaging equipment to meet certain minimal standards, including availability of appropriate maintenance.

Data Collection and Analysis

Important efforts are being made to improve the quality of data collection and analysis. PATH has worked with the cancer registry to upgrade the quality of the data for accuracy and timeliness, especially in PATH's program areas. AIHA has recently introduced

special forms for patient tracking to overcome the lack of information at the women's wellness centers on final outcomes of women referred to oncological centers for treatment. Chernihiv's oncological center, with PATH, has also introduced a mammography database (although ability to use it is vested in only one doctor).

Downstaging of Cancers

While it is too soon to expect statistics confirming the downstaging of breast cancer in the program areas—from stages III and IV to I and II—current data suggest that such results should soon be forthcoming. International experience is that statistical evidence of downstaging of cancer requires several years of implementation following initiation of a mammography screening program. It is thus too soon in Ukraine to expect such firm evidence. However, elements are in place that pave the way for such downstaging to be observed in the near future.

Recommendation: Collaborative work with the regional statistical entities should be improved.

Importance of Individual Outcomes

The value and impact on patients, families, and communities of improved outcomes for individual women cannot be underestimated. Every woman who comes into this new system will come through it better served than in the former system. Individual women benefit from earlier detection of their breast cancer, by being better informed, better supported, and more effectively treated. This cannot be forgotten. Systems improvements are harder to document at the public health level.

II. BREAST CANCER IN UKRAINE

A. EPIDEMIOLOGY

Breast cancer is the most common cancer among women in Ukraine. Furthermore, both the incidence of new cases and breast cancer mortality have increased dramatically in Ukraine in recent years. Reported incidence has more than doubled in fewer than 15 years—from about 22 cases per 100,000 women in 1986 to about 55 cases per 100,000 women in 2000. Breast cancer mortality has also increased by about 35 percent during the last two decades—from 17 deaths per 100,000 women in 1980 to about 27 deaths per 100,000 women in 1994.

While breast cancer incidence in Ukraine is comparable to that in most western countries, in Ukraine it kills proportionately more women. In this country of 50 million, 8,000–9,000 women die of breast cancer each year.

An added concern is the likelihood that breast cancer will increase due to radiation from the Chernobyl nuclear power plant disaster in 1986. Breast tissue is the third most sensitive to radiation exposure, after thyroid and bone marrow. Since increased breast cancer risk from radiation is highest among women exposed at younger ages, the potential for increased incidence of breast cancer among young girls and women ages 0–20 at the time of the accident is most likely to be realized in the first decades of the 21st century.³

In addition to direct irradiation as a potentially significant new risk factor of breast cancer resulting from the Chernobyl disaster, female Chernobyl victims have also suffered from harsh socioeconomic changes, relocation, and fear for their health as well as for the health of their family members. Women take a more pessimistic view of their future and, in particular, of their children's future, than men. Data show that 91 percent of women (versus 75 percent of men) believe that their health became worse after the Chernobyl disaster. The majority of young women exposed to Chernobyl radiation are afraid of having children.⁴

The highest concentrations of female Chernobyl victims now live in Kyiv, Kyiv oblast, Chernihiv oblast, and Zhytomyr oblast. Kyiv and Odesa oblasts have the highest concentrations of breast cancer; Odesa has 80 cases per 100,000 women.

³Long-term follow up of the survivors of Nagasaki and Hiroshima has demonstrated the positive correlation between acute, high-level exposure and increased incidence of breast cancer 10 or more years later. The Chernobyl accident issued lower doses of radiation over a longer period of time than in Japan. While direct extrapolation from Japanese experience may not be warranted, the typically long dormancy period for breast cancer suggests that an increase in incidence may be anticipated 10 or more years after exposure, with higher incidence rates among women who were young at the time of exposure.

⁴Organizing Committee under the Cabinet of Ministers of Ukraine, *Status of Women in Ukraine*, National Report for the Fourth World Conference on Women, 1995, p. 18.

B. SERVING WOMEN WITH BREAST CANCER: THE FORMER SOVIET SYSTEM

The unfortunate situation in Ukraine is not only that breast cancer incidence is high but that breast cancer is usually detected at late stages when mortality is high and when both disease-related and treatment-related morbidity are typically also high. Approximately 70 percent of breast cancers in Ukraine are detected at stage III or IV, when the chance for a cure is practically nil.

Under the traditional Soviet system of health care, which continued on in Ukraine after independence in 1991, modern approaches to breast cancer control have been lacking. Advances made in the West during the last half of the 20th century—moving away from Halstead and radical mastectomy as standards of treatment to early detection and breast-conserving procedures—did not occur in the Soviet Union. Absent were knowledge of and technology for early detection, professional awareness of and competence in clinical breast examination, access to coordinated clinical screening and evaluation centers, and coordinated, multidisciplinary treatment approaches by specialists in breast surgery, radiation therapy, and chemotherapy. Absent too were working information systems and cancer registries as well as public awareness of the importance and advantage of early detection.

Instead, as of 1995, the health care system's approach to breast cancer was characterized by inadequate screening, late detection, radical surgery, insufficient radiation therapy and/or chemotherapy, and the virtual absence of rehabilitation or counseling services. Lacking modern diagnostic knowledge and technology, mastectomy was commonly performed in advance of a confirmed cancer diagnosis—as well as when other breast abnormalities were present as prophylaxis against possible progression to breast cancer. The surgeon was the decision-maker. Mammologists (breast cancer surgeons) were a further specialization.⁵

Under that traditional system and in newly independent Ukraine, breast cancer was and remained shrouded in secrecy. Because chances of survival were so grim, doctors avoided telling women of their diagnosis, rarely even using the word *rak* (cancer) because it was commonly equated with a death sentence. Doctors might inform the husband or other family members that the reason for the mastectomy was cancer, but the woman herself might only be told it was an abnormality.

The cumulative result in newly independent Ukraine was an excess burden of breast cancer resulting from its increasing incidence and from poor systems of care and support.

This situation presented an important opportunity to improve women's health by bringing to Ukraine approaches that had become part of international standards and that are greatly reducing breast cancer mortality and morbidity elsewhere.

⁵ The Soviet system also included specialized cancer hospitals, referred to as oncology dispensaries.

III. THE GOALS AND ELEMENTS OF BREAST CANCER CONTROL

Since there is no known prevention for breast cancer, improved outcomes in breast cancer control, as ultimately measured by decreased mortality, are achieved only through treating breast cancer in its earliest stages with the most effective treatment strategies possible. This requires not only appropriate technology for early detection but also an understanding of the natural history of breast cancer and the principles of early detection and treatment, which support a belief in the value of early detection by both professionals and the public. Intervention opportunities are available at several possible places in the breast health continuum. By assuring that existing monitoring and surveillance registries track diagnosis, stage, and treatment interventions, health care leaders will be able to determine the effect of the overall breast cancer control effort.

Before decreases in breast cancer mortality are observed, specific measurable markers of success in breast cancer control may include

- measures of increased public awareness about the importance of early detection;
- implementation of curriculum change in nursing and medical schools;
- changes in professional understanding of the natural history of breast cancer and the principles of early detection and effective treatment;
- increased promotion and performance of breast self-examination;
- increased use of coordinated, multidisciplinary approaches to screening and diagnostic mammography—resulting in a trend toward smaller tumors being detected (downstaging from stages III and IV to I and II);
- increased use of fine needle aspiration (FNA) and core needle biopsies to make an accurate diagnosis before major surgery;
- use of prognostic factors, such as estrogen and progesterone receptors, to guide treatment choices;
- an increase in breast-conserving surgery;
- increased use of multidisciplinary treatment of advanced stages of cancer; and
- an accurate recording of all known breast cancer cases by stage and age of occurrence, tracking the downstaging of breast cancer from advanced (III, IV) to early (I, II).

Additional indicators of improved breast health care include the development of support and survivor groups that empower women to take responsibility for their own care and follow up, to provide emotional support for each other, and to provide support and information to women newly diagnosed with the disease or going through treatment.

IV. USAID SUPPORT: OVERVIEW

A. RATIONALE FOR USAID ASSISTANCE

Concern about Consequences of Chernobyl

The U.S. government remains concerned about consequences of the Chernobyl power plant disaster in 1986.⁶ In considering assistance aimed at mitigating Chernobyl's aftermath, the U.S. Congress, in 1996, established an earmark to provide funding through USAID "to screen, diagnose, and treat victims of breast cancer associated with the 1986 incident at the Chernobyl reactor in Ukraine" (Fiscal Year [FY] 1996 Appropriations Act).

USAID subsequently developed two activities in response:

- **The Breast Health Initiative**, designed to add selected breast cancer control activities to the services of hospitals already participating in the ongoing Medical Partnership Program of the American International Health Alliance (AIHA)—three hospitals in Ukraine (along with several hospitals in other Central and Eastern European countries), and
- **The Ukraine Breast Cancer Assistance Project**, designed to offer a comprehensive approach to improving breast cancer control in Ukraine (including screening, diagnosis, and treatment) with an emphasis on women exposed to radiation from Chernobyl. This is the activity implemented by the Program for Appropriate Technology in Health (PATH).

Need for System Improvement

USAID breast cancer support has not focused exclusively on women affected by Chernobyl. It was apparent at the outset that the Ukrainian health care system was not prepared to adequately address the needs of breast cancer patients.⁷ Given the inadequacy of the health care system's approach to breast cancer, there was a clear need for system improvements, independent of any additional burden that may result from the Chernobyl disaster. USAID analysis concluded that the implementation of a modern,

⁶The Chernobyl disaster caused an estimated 4,000 deaths among those who took part in the cleanup; 70,000 people were disabled by radiation, according to Ukrainian government figures. Overall, about 3.4 million of Ukraine's 50 million people, including some 1.25 million children, are considered affected by Chernobyl.

⁷Overall health status in Ukraine is declining, as indicated by the recent decrease in life expectancy. According to Article 49 of the Constitution, medical service is still free of charge and covered by the state. The reality is very different. The government's growing inability to finance health care has resulted in the public health budget being cut by more than half. In 1997, the government was able to provide only 55 percent of its planned budget for medical service, and only 14–15 percent for medical supplies and equipment. Hospitals and clinics lack necessary materials, funds, and medical personnel. A result is that patients are required to buy and provide supplies (e.g., intravenous bags, drugs, bandages).

cost-effective, sustainable program in breast care would be of potentially great help to victims of Chernobyl. In an environment where there is substantial underdiagnosis of breast cancer at early stages, as well as outmigration of women from the Chernobyl region, it was believed that a restricted program for only a population of Chernobyl victims would have been both difficult to implement and ethically inappropriate.

B. PIONEER EFFORT FOR USAID

Breast cancer support is a new endeavor for USAID.⁸ This means that USAID had no standards or norms for assistance in this area, in contrast to programs such as family planning and child survival, in which USAID has decades of experience. Although the United States has much to share in the area of breast cancer control, technology-centered approaches of the United States are clearly not directly transferable to resource-poor countries. Support for breast cancer control in Ukraine thus posed a major challenge for program design and implementation and has involved a great deal of pioneering thinking. How could breast cancer support and control services be improved in Ukraine in a way that is both sustainable and serves the largest possible segment of women in need? This was the challenge.

The experience that has been gained during these three years of effort by USAID/Ukraine and its implementing partners—PATH, AIHA, and the collaborating Ukrainian institutions—presents important lessons and guidance for other countries seeking to reduce breast cancer trauma and death among their women.

C. THE TWO USAID ACTIVITIES

Both PATH and AIHA aimed to increase public awareness of the importance of early detection of breast cancer, improve professional education and training of both physicians and nurses as well as the continuum of clinical services provided for the screening, diagnosis, evaluation, and treatment of women with breast diseases and breast cancer. In addition, significant efforts were also directed at improving psychosocial support services for patients and survivors and the infrastructure needed to sustain these efforts in the future.

While PATH and AIHA activities are similar in certain ways, both work in different institutions and two different oblasts. But since AIHA works in general hospitals in which cancer surgery has traditionally not occurred, AIHA does not assist in treatment (other than for benign tumors) or rehabilitation. (However, general hospitals do perform breast cancer surgery, and this has led to some competition and jurisdictional disagreement between the AIHA-supported facilities and the PATH-supported oncological centers (dispansers) in cities where both are working. (There is no competition between AIHA and PATH, but neither has there been systematic

⁸USAID had earlier provided support for breast cancer control in Poland. This may be the only country receiving such assistance. This took place under USAID's earlier Central and Eastern Europe (CEE) Partnerships in Health Care program.

collaboration or coordination. As for the facilities they support, women have the right of choice.

PATH Activities				
Implemented in Kyiv, Odesa, and Chernihiv at Oncological Centers				
Public awareness enhancement	Improved screening	Improved diagnosis	Treatment, rehabilitation	Psychosocial counseling
AIHA Activities				
Implemented in Kyiv, Lviv, and Odesa at General Hospitals				
Public awareness enhancement	Improved screening	Improved diagnosis	(Benign tumors only)	Psychosocial counseling

Of the two organizations, PATH has broader goals of training and sensitizing health professionals beyond its project sites and influencing oblast or national policy. AIHA has confined its stated objectives to its partner institutions, but it too has trained professionals in raions (districts) beyond its partner institutions (although in the same oblasts), and it had apparent impact beyond these. For example, the Odesa women’s wellness center (WWC), an AIHA partner, has spread its new screening approach and technology to the three nursing schools in Odesa. Furthermore, the Odesa oblast hospital, site of the WWC, uses residents from the Odesa medical school; thus, breast cancer screening innovations are introduced to Odesa doctors very early in their medical careers.

V. THE UKRAINE BREAST CANCER ASSISTANCE PROJECT

Implemented by the Program for Appropriate Technology in Health (PATH)

The Ukraine Breast Cancer Assistance Project (CA EE-A-00-97-00003-00) was authorized in December 1996 with a completion date of December 31, 1999 (now extended to September 30, 2000) and a budget of \$3.8 million. The project works at the national level and at four regional oncological centers—Kyiv, Odesa, Lviv, and Chernihiv—the latter being adjacent to the region in which the Chernobyl nuclear power plant accident is located.

A. GOALS, OBJECTIVES, AND PARTNERS

The Ukraine Breast Cancer Assistance Project has the following key goals:

1. Improving breast cancer screening, diagnosis, and treatment/rehabilitation services;
2. Increasing access to these services, especially among women exposed to radiation from the Chernobyl nuclear power plant accident; and
3. Enhancing the cost-effectiveness of providing these services through existing facilities and within current resource constraints.

The objectives for achieving these goals are:

1. Exchanging professional knowledge and skills,
2. Enhancing the availability of essential equipment and supplies,
3. Increasing patient understanding and public awareness of breast cancer,
4. Strengthening the health infrastructure,
5. Refining relevant policies and practice guidelines, and
6. Providing breast cancer survivors with information, psychosocial support, and opportunities to meet with each other.

PATH's original partners were

- the Ukrainian Center for the Diagnosis and Treatment of Breast Disease (UCDTBD)—the breast cancer center within the Ukrainian Research Institute of Oncology and Radiology in Kyiv,
- the Chernihiv Oblast Oncological Center (dispanser) (COOC)—Chernihiv oblast is a focus of radiation exposure from the Chernobyl accident, and
- the Odesa Oblast Oncological Center (dispanser)—Odesa oblast has one of the highest incidence rates of breast cancer in Ukraine.

During its work, PATH has also established collaboration with the Kyiv City Oncological Center (KCOOC) and Lviv State Medical University, Pathology Department.

B. KEY ACCOMPLISHMENTS

Emphasis has been on enhancing breast cancer services in both preventive and therapeutic care. The major actions reinforced screening modalities for early cancer detection in more treatable stages using clinical and mammography breast examination. Program highlights include the following:

- **Training:** PATH has provided a substantial range of training for personnel in both its partner institutions and representatives from up to 18 oblasts. (See annex B.)
- **Breast cancer screening project:** Collaboration with COOC to establish breast cancer screening for a defined population of women. The project hopes to demonstrate an increase in early detection of breast cancer through clinical breast examination and mammography.
- **Mammography strengthening:** The team has contributed significantly to the quality of mammographic screening and diagnosis by providing equipment, supplies, and training in mammography screening and diagnosis for technicians and radiologists. In the process, the team and its partners confront the challenges of encouraging the development of a sustainable technical maintenance and supply procurement infrastructure for mammography.
- **Clinical breast examination support:** Over 1,100 health care professionals have been trained in clinical breast examination (CBE) at several training sites throughout Ukraine, using a curriculum that PATH developed.
- **The clinical team approach:** PATH has demonstrated the team approach to the clinical management of breast cancer. Specialists in surgery, oncology, radiology, and pathology have demonstrated the value of collaboration.

- **New approaches to breast cancer pathology:** PATH has provided training, equipment, and supplies for upgrading pathology diagnostic services. Fellowships in Seattle and symposia in Ukraine have exposed a small cadre of Ukrainian pathologists to immunocytochemical diagnostic techniques. Equipment and supplies were delivered which established activity centers in immunocytochemistry in three of the project sites (Kyiv, Odesa, and Chernihiv).
- **Patient educational and public awareness IEC literature** have been produced. Over 250,000 copies of various culturally adapted brochures have been distributed to patients and healthy women at risk. (See annex B.)
- **Psychosocial support:** PATH work in encouraging peer support for breast cancer survivors has evoked a positive response in Ukraine. The PATH contribution primarily has been training in psychosocial support for health care workers and peer volunteers. PATH has promoted regional consultation and exchange of Ukrainian health workers and breast cancer survivors with their Polish and Russian counterparts.

Additional highlights include:

- By January 2000, a PATH pilot screening program based at COOC had evaluated 3,831 women by screening mammography and had detected 90 cancer cases since screening began in July 1998. A public awareness campaign to increase early detection of breast cancer accompanies the breast cancer screening activity. The Odesa Oblast Oncological Center has screened 1,878 women using mammography and has identified 49 cancer cases.
- The Odesa Oblast Oncological Center evaluated a standard American neoadjuvant chemotherapy protocol involving detailed monitoring of 30 patients.
- PATH has provided training in psychosocial issues for medical providers and for breast cancer survivors interested in becoming outreach volunteers.
- Opportunities were arranged for professional exchanges between Ukrainian, Polish, and Russian advocates and health professionals in the breast cancer field.
- A national summation conference on the breast cancer project was convened in Kyiv, November 9–11, 1999, and was attended by 120 Ukrainian health care workers and breast cancer survivors.

PATH activities have also included assistance in

- the standard cancer database system implementation,

- essential laboratory support for diagnostic work-up and patient monitoring during treatment,
- a pilot project on implementation of a standard U.S. chemotherapy protocol (neoadjuvant chemotherapy),
- psychological counseling, and
- provision of equipment and supplies for mammography screening and diagnosis and for upgrading pathology diagnostic services.

Leveraging of Other Funds

PATH has leveraged funds from sources other than USAID to complement its work. In-kind contributions and cofunding totaling \$367,000 had been raised through July 2000. For example, PATH has sought and received support from other institutions for training for project personnel (e.g., Chernihiv's junior radiologist has received a fellowship for training in Seattle from the International Union Against Cancer). To support breast cancer survivor groups, PATH raised more than \$16,000 from friends and colleagues, which it presented in small grants to six groups.

C. IMPACT

PATH considers that the two main benefits of its work are strengthening of CBE for promotion and use nationwide and support to the survivor groups and self-help movement. These indeed appear likely to have major impact; both are low cost and likely to be sustained. While technology-oriented personnel will be advocating greater use of mammography, cost and quality are likely to pose issues.

VI. THE BREAST HEALTH INITIATIVE

Implemented under the Medical Partnership Program of the American International Health Alliance (AIHA)

Since 1992, the American International Health Alliance (AIHA) has supported partnerships between hospitals and medical centers in the United States and in the new independent states (NIS), including Ukraine. USAID has supported AIHA's Medical Partnership Program through a cooperative agreement (CA EURO-0037-A-00-4016-00). The Breast Health Initiative was launched in 1997 as an additional component of the ongoing Medical Partnership Program. It was created in large part in response to U.S. Congressional directives and was funded by USAID at a total level of \$2.5 million. After the Medical Partnership Program ended in spring 1998, the breast cancer activities were continued under a sustainability grant.

A. GOALS AND OBJECTIVES

The overall objective of AIHA's Breast Cancer Initiative is to develop comfortable and easily accessible outpatient centers that provide breast cancer screening, including mammography, and a full range of educational materials related to breast cancer prevention, detection, and treatment.

Specific objectives are to:

1. Develop a full range of educational materials and programs, including school-based and public awareness programs to educate women concerning the risk of breast cancer and the need for self-detection;
2. Develop and implement a model screening and early detection program with a cost-effective mix of techniques and technology, including mammography and ultrasonography;
3. Develop professional education programs for radiologists;
4. Develop programs to address the psychological aspects of breast cancer and treatment;
5. Implement continuous quality improvement (CQI) programs and management training needed to sustain and expand the program at each of the partnership sites;
6. Develop financial and economic analysis to assess cost-effectiveness of the partnership pilot programs; and

7. Create a patient tracking system that can be linked to relevant breast cancer registries and other relevant data sets and that can provide critical insight into the impact on morbidity and mortality.

B. THE WOMEN'S WELLNESS CENTERS

Sites chosen for the women's wellness centers (WWCs) and the Breast Health Initiative were

- the Odesa Oblast General Hospital (in partnership with Coney Island Hospital; the WWC opened in 1998),
- Lviv Railway Hospital (in partnership with Buffalo: Millard Fillmore Health System; the WWC opened in 1998), and
- Kyiv Center for Maternal and Child Care, Left Bank (in partnership with Philadelphia: University of Pennsylvania Medical Center; the WWC opened in April 1999).

The four main goals of the women's wellness centers are to

- prevent poor pregnancy outcomes,
- prevent unintended pregnancies and abortions,
- prevent sexually transmitted infections, and
- encourage healthy lifestyles across the continuum.

An AIHA women's task force group has been created (comprised of women's health clinicians, managers, and educators associated with the AIHA partnership program) to develop a model for comprehensive women's wellness centers. The task force recommends that the following services be provided by a center:

- Family planning and reproductive health, including fertility education and contraceptive services;
- Perinatal care, including prepared pregnancy and childbirth classes and breastfeeding;
- Sexually transmitted infections/HIV/AIDS prevention, detection, treatment, and management; and
- Cancer screening and education, including pap smears, clinical breast examination, mammography screening and/or referral, and breast self-examination education.

Throughout Ukraine, the health care system includes a facility, usually inside a clinic or polyclinic, called Women's Consultation. The women's wellness centers developed from

these but, in comparison, provide more up-to-date, integrated, comprehensive, and preventive services that aim to be community oriented, women centered, and women friendly and to address all women's health needs throughout the life cycle. Women interviewed at the Odesa WWC expressed enthusiastic satisfaction with the care and integrated services offered.

C. KEY ACCOMPLISHMENTS

AIHA lists the following major activities and achievements:

1. Study tours to the United States for head physicians and relevant regional and national health administrators and ministerial officials to learn about program components, their potential applicability to Ukraine, and their integration in a comprehensive service model (January 1997, South Florida);
2. Training visits to U.S. partner institutions for WWC health professionals and designated trainers to improve diagnostics and treatment skills and to prepare for training-of-trainer programs;
3. Purchase and installation of major equipment and delivery of supplies for each of the three WWCs; specifically, state-of-the-art mammography unit (Trex-Bennet company), Kodak developer machine, General Electric (GE) Ultrasound with 7.5 Hz probe for breast and thyroid gland, additional supplies for mammography (phantoms, view boxes) and diagnostic procedures (biopsy, aspiration, wire localization), Kodak films and solutions for film development and machine maintenance, and disposable gowns, pads, etc., for hygienic purposes and patient comfort;
4. In-country comprehensive training programs addressing early detection and treatment options for physicians, nurses, radiologists, technicians, and others conducted by U.S. and Ukrainian pilot site trainers;
5. Coordination and support for dissemination conferences and workshops in Ukraine, including an NIS regional conference;
6. Development of breast cancer screening guidelines and algorithms, based on the standards of the American College of Radiology, adapted for Ukrainian medical terms and practices and organization of a joint Ukrainian–American task force group for guidelines development and revision (Washington, 1998, and Lviv, 1998), and dissemination of the guidelines and performance algorithms to the breast care centers' staffs;
7. Information support, such as computers and Internet access;
8. Assistance in the development of databases and patient tracking systems; and

9. Assistance in the development and reproduction of public and professional educational materials and programs.

Outcomes

AIHA lists the following outcomes:

1. Increase in public awareness of breast cancer problems and possible methods of treatment;
2. Improvement of the level of expertise of health professionals;
3. New services offered to women, such as breast screening;
4. Increase in the detection of breast cancer in stages I and II (see section VII);
5. Increase in referrals to existing centers in Kyiv, Lviv, and Odesa;
6. Decrease in the development of lymphedema with subsequent early recognition and treatment of cases that do exist; and
7. Decrease in mortality associated with breast cancer.

D. THE PARTNERSHIP MODEL⁹

Both AIHA staff and Ukrainian partners describe partnership as a process roughly akin to marriage: there is a first meeting, a getting-acquainted phase, perhaps a phase of impaired communication accompanied by a few problems, and finally, a deep and enduring relationship. One Ukrainian partner, when asked how long the partnership would continue, replied, “If this word means funding, then it will continue as long as there are funds available for us to work together. If we are talking about friendships resulting from the partnership, they should go on forever.”

⁹“The AIHA partnership model...includes the use of volunteers rather than paid consultants, an institution-to-institution focus, and a structure that encourages collaboration and sharing of information among partners. It differs significantly from typical development projects funded by USAID. The idea was to find institutions against which to exert a critical mass of resources, with the prospect that each would bring about change, acquire an energy of its own, and eventually have some impact on the landscape of health care in the NIS... The model has a number of positive attributes, including a high level of volunteerism and an impressive level of private resources leveraged. The partnerships are built on mutual interest and the thirst of the NIS/CEE partners for knowledge of Western clinical and managerial practice. They are a politically popular way of delivering foreign assistance. However, the model also has an inherent limitation. The cultural and technological gulfs to be bridged and partners’ limited international experience made for slow starts in many instances. Further, the respective health care systems are radically different in operation and mentality. There can be disincentives to sharing information among NIS/CEE institutions. U.S. health care professionals may well have less time for volunteer work in the future.” M. Butler et al., *Evaluation of the American International Health Alliance (AIHA) Partnerships Program*, for USAID, January 30, 1988.

Although the present evaluation was not intended to evaluate AIHA activities in depth, little or no evidence of problems was found on the Ukrainian side. Indeed, the driving motivation on the part of Ukrainian partners of thirst for knowledge was fully evident. (Interviews with U.S. partner institutions were not part of the scope of work for the evaluation.) When pressed, Ukrainian partners would reply that they only wished the partnership had started earlier or was funded at levels that included more institutions and more oblasts. Ukrainians from partner institutions and AIHA seemed enthusiastic and committed to the importance of what they are trying to accomplish.

The AIHA–assisted partnerships have fostered a process of self-selection for people who are self-confident, activist, reformist, positivist, bright, and committed. AIHA partners appear to feel a sense of pride and ownership of the women’s wellness centers.

E. THE FUTURE: FROM HOSPITAL-BASED WOMEN’S WELLNESS CENTERS TO PRIMARY HEALTH CARE CENTERS

AIHA is moving away from its hospital-based partnerships (and women’s wellness centers) to community partnerships and primary health care centers.¹⁰ The emphasis will be on primary and secondary prevention of disease, with some special disease emphases depending on the site and the population served (e.g., lung disease in a coal-mining area).

The women’s wellness centers should remain part of and assist transition toward a primary health care approach.

¹⁰AIHA takes its definition of primary health care from the U.S. National Academy of Sciences, Institute of Medicine (1996): “...the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community.”

VII. THE BREAST CANCER CONTROL CONTINUUM

Observations and Conclusions Concerning Approaches to Breast Cancer Control in Ukraine

Both PATH's Ukraine Breast Cancer Assistance Project and AIHA's Ukraine Breast Health Initiative were intended to improve outcomes for women with breast cancer in Ukraine. A comprehensive approach was taken with activities directed at increasing public awareness of the importance of early detection of breast cancer, improving professional education and training of both physicians and nurses concerning breast cancer in general and, specifically, the importance of good clinical skills in breast examination and patient communication. In addition, activities were directed to the continuum of clinical services provided for the screening, diagnosis, evaluation, and treatment of women with breast disease and breast cancer. Significant efforts were also directed at improving psychosocial support services for patients and survivors and the infrastructure needed to sustain these efforts in the future.

As described in annex A, Methodology, the evaluation team visited PATH and AIHA sites in Odesa, Kyiv, and Chernihiv, and interviewed administrators, physicians, nurses, technical support staff, patients and survivors, project staff at each of these sites, and team members from the Lviv site, while they were attending conferences in Kyiv. The team met with USAID staff and stakeholders; supporting documents from both PATH and AIHA were made available as well. The team attended several conferences in Kyiv that were scheduled during the evaluation (conferences on psychosocial support services and breast cancer survivorship, a breast health case study review workshop of AIHA partners, and the breast cancer portion of the NIS oncology conference).

From these efforts, the evaluation team was able to observe the continuum of comprehensive activities aimed at improving breast cancer outcomes for women in Ukraine. These breast cancer control activities are discussed in detail in this section as well as observations and findings on which conclusions (summarized in section I above) are based.

Conclusion: An important lesson learned is that a comprehensive approach to breast cancer control will have far more impact than a piecemeal approach concentrating on only one component. In addition, screening, whether through mammography or CBE, must be linked to multidisciplinary evaluation and treatment services. Early detection of breast cancer without effective therapy is insufficient to improve breast cancer mortality. Moreover, it would be unethical to introduce improvements in access to screening services aimed at the early detection of breast cancer without also assuring that women have access to effective treatment services.

A. CHANGING KNOWLEDGE AND ATTITUDES

Increasing Public Awareness

Both PATH and AIHA have worked to increase public awareness of the importance of breast cancer early detection. PATH developed numerous tools and approaches for educating the public about breast cancer, drawing upon its institutional expertise in information, education and communication (IEC) development in crosscultural settings. PATH developed 30-second television and radio spots and over 250,000 copies of printed items, such as posters, pamphlets, and booklets. Printed materials have been available, primarily in clinical settings. Strategies for making these available in the broader community (e.g., at shops, bus stations, and post offices) are being considered and have already begun in Chernihiv.

PATH also developed and conducted a public awareness campaign during all phases of implementation. The primary message is that breast cancer can be curable if it is diagnosed at an early stage. PATH conducted client-centered market research, using focus group discussions and baseline surveys, to choose appropriate media and to develop culturally appropriate IEC materials for its public awareness campaign.

Televised roundtable discussions are a common method in Ukraine for educating the public about health issues. Yet before the two USAID projects, there had never been one about breast cancer. Nor apparently had there been one on any cancer that used the term rak (cancer). PATH introduced the word rak for the first time in a public media discussion of breast cancer. Programs sponsored by USAID activities had hotlines urging the public to call in live with questions about breast cancer. The public awareness campaign also resulted in an increased comfort level for both women and professionals in talking about breast cancer and accessing breast evaluation services.

AIHA has pursued parallel and complementary public awareness strategies. It has distributed three types of print materials: those developed by PATH (with reprint costs paid by AIHA), materials from the United States obtained during visits to partner institutions, and materials developed by AIHA Ukrainian partners themselves, as in Odesa. AIHA Ukrainian partners have also participated in televised roundtable discussions. An important step in public awareness raising was the workshop on breast health community outreach for health care providers of the women's wellness centers and primary care facilities with a separate session for mass media representatives. An outcome of the workshop was articles and television spots by journalists who attended. AIHA partners at the breast health community outreach workshop were trained in how to raise funds for public awareness campaigns and the survivors' movement.

The impact of public awareness efforts of both USAID activities can be measured in increased numbers of clinical breast examinations and mammograms performed. In Odesa, the increase in public awareness seems to have resulted in increased use of mammography services at both Odesa facilities: a twofold increase in referrals for mammography at the oncological center, and 2,455 mammograms at the WWC through

March 2000. Contributing to the increased referrals at both WWCs and oncological centers have been increases in clinical breast examination (CBE) performed by nurses and feldshers and obstetricians/gynecologists in the community (discussed below).

To measure the impact of public awareness initiatives in Chernihiv, PATH conducted a baseline and follow-up survey of the population. Analysis of findings is in progress and a report (*Screening Survey for Women in Chernihiv, Baseline and Follow Up*) should be available soon.

Another result of increased public awareness efforts appears to be the formation and continuing activities of support groups of breast cancer survivors. These groups also add to the spread of public awareness by visiting oncology wards and speaking to women about their own experiences. These women volunteers emphasize the message of hope that breast cancer can be more successfully overcome today through earlier detection and treatment. In addition, several articles have appeared in the local press about the survivor groups.

Sustainability

Better tools for educating the public about breast cancer are now in the hands of PATH and AIHA partner institutions, especially PATH partners in Chernihiv and Odesa. These partners especially know how to develop IEC messages and materials, targeting segments of the general public through specific, internationally employed methods, such as focus group research. These methods could be used to develop campaigns related to other health concerns.

The cost of continued public education about breast cancer is an important issue. Television and radio time are free for the most part. Many broadcasts have been on local stations at the oblast level. Funds will be needed to replace and print additional materials. Where these will come from remains an open question.

PATH and AIHA partners have also learned more about how to use mass media for positive publicity for breast cancer. There were deliberate attempts to enlist and involve the press in order to get useful exposure beyond that subsidized by project budgets. There have been newspaper articles (not always to the projects' liking) as well as radio and television discussions that for the most part helped further the cause of public awareness of the value of early detection. At least one member of a breast cancer survivor support group happens to be a radio journalist; she has helped get free air time to spread the message in Chernihiv oblast.

A recent article in the Ukrainian press illustrates the type of coverage that breast cancer now receives:

Breast cancer is the leading cancer in Ukraine: 53 cases for every 100,000 women (which is comparable to other countries) but breast cancer mortality consumes 8,000–9,000 Ukrainian women, annually. This means that in 10 years the estimated number of women who die as a result of breast cancer will equal the population of a city such as Bila Tserkva. The tragedy is that most

of those who die will be women 40–45 years of age. Breast cancer is one of the main causes of death among working women.

Why is this so? The reasons for the premature deaths include late diagnosis, lack of mammography equipment, the indifference of health authorities toward the problems of breast cancer, and the neglect of Ukrainian women of their health. Unfortunately, most of our women pay visits to a doctor when they are already in stages III and IV of breast cancer when, as doctors say, the cancer is screaming out. If it were caught earlier, the treatment would be cheaper and shorter, and surgery less traumatic physically and psychologically. But most important of all, a woman would have a much better chance at not only surviving, but at also having a better quality of life. (*Mirror Weekly* No. 47, November 27, 1999, translated in PATH Quarterly Report October–December 1999, attachment 7.)

Conclusion: At both the local and national levels, public awareness of the importance of early detection of breast cancer and knowledge of where to go for screening, evaluation, and care has been increased. Breast cancer is increasingly discussed as a problem that can be approached positively, rather than either ignored or approached with fatal resignation. Successes at the local level are indicated by both data and the perception that there is increased demand for services (both screening and evaluation of problems). Increased media coverage is not only a means to increase awareness but also evidence of emphasis being placed on early detection. Recently formed breast cancer survivor groups are also contributing to public awareness.

Recommendation: The MOH, partner institutions, and survivor groups should continue efforts to build public awareness on the value of early detection. The public education efforts should also include efforts to explain established risk factors for breast cancer and to encourage those women who are at increased risk, owing to their exposure to radiation from the Chernobyl accident, to be evaluated.

Patient Education, Counseling, and Psychosocial Support

Dramatic changes have taken place concerning women in the whole spectrum of breast cancer control. This is one of the most important innovations that has occurred because of PATH and AIHA support.

Under the Soviet system, women were more or less passive victims of the disease, being struck by it when chances for survival were usually slim and consequently, were not being informed by the doctor of their diagnosis. In medical school, students were taught that they should not tell a woman of a breast cancer diagnosis and it appears that there was a directive under the Soviet system forbidding doctors from doing so. Doctors also did not want to tell the woman of her diagnosis given that cancer usually meant death.

When USAID support began in 1997, very little attention was being given to meeting either the informational or emotional needs of women with breast cancer. There was no such thing as informed consent. Doctors still avoided discussing breast cancer with patients, hospitals had no psychologists or social workers, and support groups were nonexistent.

Today, a major paradigm shift is underway. Women are learning about the disease, diagnosis, and treatment options and are becoming empowered to challenge and change the system. PATH's work in this area is one of the major achievements of USAID support. AIHA, too, has contributed in this area, putting emphasis on breast health in conjunction with its three women's wellness centers.

Patient Educational Materials: Providing Needed Information

Prior to USAID assistance, almost nothing existed that patients, their families, or women in general could read about breast cancer and the many elements of breast cancer care. To meet these informational needs, PATH developed a wide range of culturally adapted brochures and leaflets (see annex B). Over 250,000 copies have been distributed by both PATH and AIHA. AIHA partners have reprinted many of these and developed their own. This is one benefit that extends far beyond the four USAID–assisted oblasts. Not only are these attractive, easy-to-read materials available in various facilities throughout Ukraine, but they have found their way to many neighboring countries as well, shared not only by PATH and AIHA but by other organizations that recognize their value to women who otherwise have no such information.¹¹

AIHA and PATH have worked together to make educational videotapes available, emphasizing the importance of early detection and providing guidance in breast self-examination. Both have provided participating facilities with televisions and videotape cassette recorders for patient and public education. Both AIHA and PATH have provided partner facilities with anatomical breast models that women and providers alike can use for hands-on training in palpation (lump detection). AIHA has organized, equipped, and furnished patient education rooms in WWCs. It organized similar rooms for inservice education of primary care professionals in clinical breast examination, breast self-examination, and related subjects.

Psychosocial Training for Nurses, Doctors, and Other Professionals

An important contribution of USAID assistance has been making doctors and nurses more candid, comfortable, and competent in talking with patients about breast cancer and in providing both factual information and psychological support. At the same time, other professionals (psychologists and social workers) are also being brought in to assist. PATH has played a major role. Its contributions have been in both

- preservice training—integrating psychosocial aspects of breast cancer care into the basic education and postgraduate curricula for nurses and doctors; and

¹¹For example, the Women's Information Consultative Center, a women's NGO in Kyiv, has shared copies with other women's NGOs in countries from Lithuania to Kazakhstan as part of its Empowering Education training activities. Its founder reports that the Women's Information Consultative Center does not work directly on health but that these materials are very important for women's empowerment. She reports that they have been reprinted in publications of women's groups throughout the region: "It's a chain of information that never stops."

- inservice training, especially
 - a 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),
 - a Kyiv symposium on breast cancer psychosocial support (May 2000), and
 - psychosocial training workshops for nurses in Kyiv (scheduled for August 2000).

The impact is twofold. First, a new norm has been established for Ukraine. Second, the major oncological facilities in Kyiv and the other three participating oblasts have accepted this new norm and their doctors and nurses are following it.

Informed Consent

PATH has also introduced the idea and practice of informed consent in two of its partners, Odesa and Chernihiv oncological centers. In Odesa, PATH introduced informed consent for patients participating in the neoadjuvant chemotherapy protocol. In Chernihiv, it is now routine that breast patients are counseled about their diagnosis and options, participate to various degrees in decision-making, and indicate their consent by signing an informed consent form.

Additional Personnel for Counseling

Some partner facilities are using volunteers to provide additional counseling and support. Chernihiv's oncological center (dispanser) is perhaps the best example. With PATH support, it has trained members of a breast cancer survivors' group to be regular visitors to the wards, counseling women about to undergo mastectomies or other treatment or who are in recovery. Volunteer programs are also underway in Kyiv and Lviv through PATH support.

The women's wellness centers place special emphasis on informing and counseling women about their health, including breast health. Each WWC has a psychologist on staff. At the Kyiv center is a nurse-midwife (on staff) who directs the educational function. This includes breast health (the importance of early detection of breast cancer and training in breast self-examination) along with family planning, modern approaches to childbirth (Lamaze, father participation in delivery, rooming-in, and breastfeeding), and healthy lifestyle counseling (including nutrition, smoking cessation, sexually transmitted disease [STD] and human immunodeficiency virus [HIV] avoidance). The

Kyiv WWC is now setting up a psychological support group for breast cancer patients that will be led by a volunteer survivor. In Odesa, the women's wellness center offers counseling through a volunteer who comes to the center on Saturdays. An advertisement has been run in the local paper inviting breast cancer survivors to join a support group, but the response to date has been from healthy women seeking information. AIHA is also setting up hotlines. It has provided training on hotline consultation for the centers' staffs and installed additional telephone lines at the centers; the hotlines are to begin operating by September 2000.

Candor versus Concealment of Truth: Sustaining and Spreading the New Thinking

Most doctors and nurses who have participated in training on psychosocial aspects believe that it has resulted in positive benefits; trust and empathy are likely to develop with the patient and communication is facilitated. Yet some providers see this additional psychosocial effort as making breast cancer management more difficult and time consuming. This may be especially true on the part of busy providers or those who are less skilled communicators.

Moreover, this process empowers patients and some doctors may prefer to deal with silent, passive patients, as under the former Soviet system. Older doctors in particular are accustomed to that approach and typically believe that it is easier for them personally not to have to deal with strong emotional reactions to a cancer diagnosis. (For example, a doctor interviewed in Odesa told of finding himself with a patient who fainted after learning she had breast cancer.) There is frequent reference in Ukraine to a patient who committed suicide upon learning of her breast cancer diagnosis.

Breast cancer survivors who have participated in PATH training strongly believe that health professionals should be honest in telling women if they have breast cancer. This should be done in a gentle, sensitive way—but it should be done. During this evaluation, many survivors spoke passionately on this subject in interviews, at stakeholders' meetings, and at a major conference, saying that most women, even if fearful, want to be full partners in decisions concerning their health and lives.

Yet even these survivors acknowledge that some Ukrainian women do not want to know their breast cancer diagnosis and emphasize that women have a right not to know as well as to know. One survivor from Chernihiv estimated that about 1 percent of women fall into this category, although doctors may believe that the percentage is significantly higher. The survivors who have been active in providing patient counseling explain that in the absence of a supportive structure (such as the breast cancer survivor groups provide), some women simply do not want to hear a cancer diagnosis or details. For example, one patient interviewed by the evaluation team in Odesa (who had not been visited by a survivors' support group) said she wanted only the bare basics of a breast cancer diagnosis, not any depressing details—but she had not been exposed (as are patients in Chernihiv) to the beneficial effects of counseling from survivor groups.

It must also be acknowledged that oncology specialists have very large patient loads. One survivor characterized treatment as an assembly line. She believes that a third person, such as a trained psychologist, is needed to mediate between doctor and patient. For their part, many doctors say they lack the skill as well as the time to communicate with patients.

While much progress has been made in the four USAID–assisted oblasts, throughout most of Ukraine a wall of resistance and the old pattern probably remain of not telling a woman her breast cancer diagnosis—or of using only vague or obfuscating medical terms intended to convey little to the patient. PATH and local partners believe that they are breaking down this wall bit by bit, but the whole issue is still under discussion nationally, according to a leading educator in psychosocial counseling.

Conclusion: Patients in the partner hospitals generally are better informed and more knowledgeable about breast cancer than previously and more so than in other hospitals today. The new emphasis on patient education, counseling, and psychosocial support and on involving patients in treatment decision-making is an important advance in cancer care. In the most progressive facilities, patients are (and feel) much more involved in the diagnosis and treatment decision-making process than they had previously. The challenge is to have this adopted beyond the four USAID–assisted oblasts. PATH has begun this expansion process by holding two national symposia on patient education and psychosocial support, but more will need to be done before these major changes in new attitudes and procedures are adopted in all oblasts.

Recommendations

- The breast cancer curricula should continue to include emphasis on psychosocial aspects of breast cancer care.
- Standards for Centers of Excellence should include not only standards for technology but also for patient education and psychosocial support.
- The educational materials should be shared with other countries.

Professional Education and Training

Professionals involved in breast care in partner institutions in the four project areas have substantially increased their knowledge and skills regarding CBE, the natural history of breast disease, early detection, new treatment approaches (in PATH project areas), and psychosocial support. There have been equally important changes in attitudes and mindsets as needed to back off from radical mastectomy as a standard and espouse more modern breast-conserving approaches.

Both PATH and AIHA have trained various primary health care staff in CBE: obstetricians/gynecologists, feldshers, nurses, laboratory technicians, and midwives. It

has most often used the training-of-trainers approach to maximize impact. That is, health care providers trained by the projects have in turn trained peers at other levels and locations (health post or FAP; general hospital at city, raion, or oblast level; or educational institution).

The training of trainers has been accomplished through various seminars and symposia, study tours to the United States, regional study tours and symposia (e.g., in Poland), and special training sessions for specialized personnel (e.g., ER/PR test training for laboratory technicians). Indeed, a major proportion of efforts and resources of both projects has been devoted to upgrading and training of Ukrainian health personnel.

Both USAID activities have trained specialists in all aspects of mammography. PATH has trained mammography technicians and radiologists on proper patient positioning, quality control, and reading/interpreting mammograms and has developed training manuals for the participants. PATH has trained radiologists in ultrasound guided needle biopsy. It has also trained pathologists in immunocytochemistry and histology. In the area of rehabilitation, PATH developed materials and provided some training on exercise for restoring full range of motion, on diet and general health, and on avoiding lymphedema. (See annex B.)

This training effort is changing attitudes and practices among professionals at project sites, permitting a higher quality of patient care along the continuum of care. Evidence of this can be found among both health professionals and patients at project sites. For example, health professionals in partner institutions seem to accept an enhanced role of the breast cancer patient. They seem comfortable with a patient that is active and participatory, self-aware and self-confident, and has high levels of expectation for patient–professional communication and positive treatment outcomes. However, the empowered, more aware patient can be seen by some doctors as making breast cancer management more difficult and time consuming. Some doctors prefer the passive patient and so are resistant to some aspects of training, or at least to its application with patients.

Conclusion: A major effort in training and educational activities has resulted in substantial improvement of knowledge, attitudes, and skills of physicians, nurses, and other providers involved in breast cancer, especially in the USAID–assisted oblasts. Many personnel who previously had only read of the new advances have now gained first-hand knowledge and developed hands-on skills and competence. CBE training has been improved.

Recommendations

- The breast cancer curriculum for medical students needs to be strengthened at all levels and made consistent with international standards so that there can be sustained impact. Communication with peers in the United States and Eastern Europe, initiated and facilitated by PATH and AIHA, must continue in order to keep the Ukrainian leaders in this transformation motivated and abreast of new developments.

- The regular, inservice refresher training for all specialists (doctors, radiologists, nurses, technicians, and feldshers) should be based on and thus consistent with the strengthened curricula used for basic training of doctors and nurses.

Sustainability of New Knowledge, Attitudes, and Practices

If new ways of thinking about and managing breast cancer indeed lead to earlier detection, improved treatment outcomes, and more satisfaction on the part of patients (and their families), this in itself should make health care providers want to sustain and share new knowledge, attitudes, and practices.

The introduction of CBE by the PATH initiative into the curricula of nurses, medical students, and continuing education for physicians has provided the future educational groundwork for integrating CBE more completely into the daily practice of the primary care community as well as its specialists.

The establishment of electronic mail and Internet communication between Ukrainian and U.S. partners, as well as provision of computers and related training, should also help sustain changes and allow for additional ones. AIHA will continue to implement health programs in Ukraine, using its partnership model. Therefore, professional contact—including direct personal contact—will continue with Ukrainian AIHA partners over the next few years, even if different individuals and institutions are involved.

B. CLINICAL SERVICES CONTINUUM

Clinical services directed at breast care usually begin with physical examination of the breast (clinical breast examination) and follow with breast imaging, as indicated. Screening mammography is usually not appropriate under the age of 40 unless there are specific risks or clinical conditions that indicate that imaging would be useful. Diagnostic mammography and breast ultrasound are usually available where screening mammography is performed to permit prompt evaluation of screening abnormalities or to evaluate palpable abnormalities referred by primary care or specialty providers who have examined the woman. Multidisciplinary evaluation of a woman with a palpable abnormality by CBE or an abnormal screening mammogram provides a coordinated approach to differentiating malignant from benign breast disease and to making proper recommendations for either further evaluation, for example, biopsy, or follow up of breast disease suspected to be benign.

Biopsies, when indicated, are usually best performed in a multidisciplinary setting where the mammographer, the ultrasonographer, and the surgeon who have seen the patient are able to confer on the best approach. This is particularly important with nonpalpable abnormalities, which may be seen only on mammography or ultrasound. Biopsies that reveal cancer will prompt referral for treatment and will usually involve oncology specialists in surgery, radiation therapy, and sometimes medical oncology. The hallmark of an evolved breast care system is the multidisciplinary involvement of providers

interested in breast health care and systems of evaluation that result in the effective treatment of early stage disease.

Clinical Breast Examination

A standard approach to CBE has been developed and use of CBE, as a standardized technique, is now more widespread in Ukraine. CBE is now being performed properly in many primary care settings (FAPs and others) by a variety of personnel (obstetricians/gynecologists, nurses, feldshers, and midwives) trained through substantial inservice training efforts (including training of trainers) by both USAID-supported activities. Widespread, improved CBE at primary care levels, a result of both PATH and AIHA efforts, should help find more early stage breast cancers. These cases now have an increased likelihood of being diagnosed more accurately and treated more appropriately in project sites.

Because of PATH's efforts, CBE is now institutionalized in the nursing schools. CBE has been included in the nursing curricula and a core group of trainers has been trained in this new curriculum. They are expected to continue training health providers in both CBE and breast self-examination. Many nurses in the 27 basic oblast nursing schools have been trained in the new CBE curriculum (as well as in psychosocial support of breast cancer patients). This should help spread the new approach for screening (or technically, for increased case discovery) to other oblasts. Ukraine's adoption of a new CBE curriculum in its nursing schools might be the most sustainable part of PATH's work.

The new approach to CBE has also been introduced in some medical schools, but efforts are still needed to institutionalize CBE training nationwide in the medical school curricula.

Student and inservice training in CBE is done through lectures, slide and videotape presentations, and hands-on learning with silicone model breasts (supplied by USAID activities) and live volunteers.

A major question arising from the two USAID-supported activities is how much impact CBE can have in screening, with and without linkage to improved mammography technology. This question is important because Ukraine cannot afford widespread screening mammography at this time and is not likely to be able to afford it for at least the next few years.

Given economic constraints, PATH believes that Ukraine should move ahead with full commitment to CBE as the primary mode of screening—focusing Ukraine's limited mammography capability on diagnosis. PATH believes that CBE (which it sees as including educating women about breast self-examination) is more sustainable and economically viable than mammography. PATH also believes that screening through CBE and BSE—even without screening mammography—can make a difference in downstaging (finding breast cancer at early stages). PATH cites studies which show that

CBE, when performed properly, can find at least half of the tumors found through mammography.

In contrast, AIHA and its Ukrainian partners do not seem to believe that CBE without mammography can make a significant difference. AIHA regards CBE as an important diagnostic tool; all of the physicians at AIHA sites have been trained in CBE. But AIHA does not see such an important role for CBE as does PATH.¹²

The three-year period of USAID support has been too short to provide convincing evidence to answer this or other broad questions. Indeed, this question and a related question about the measurable effects of widespread, long-term mammography on mortality are still being debated internationally.

Conclusion: Given the cost of both purchase and maintenance of mammography equipment, which will remain beyond the means of Ukraine for the foreseeable future, CBE will be very important for screening and early detection of all but the smallest, nonpalpable cancers (stage II and above, and some stage I). Important measures have been taken to improve the effectiveness of CBE. In the four oblasts supported by PATH and AIHA, a model for low-cost breast cancer screening through CBE has been established that includes public awareness, client counseling, and provider competence at all levels. PATH developed a comprehensive CBE curriculum with a slide set and CBE has now been established in the nursing curricula; representatives of many basic oblast nursing schools (27) in Ukraine have been trained in CBE. This will help spread the model to other nursing schools over time. CBE has been included to a lesser extent in medical schools.

Recommendations

- CBE, performed correctly, should be emphasized as an essential component of the complete physical examination of women over 18, and as critical to a comprehensive approach to the early detection of breast cancer, which includes physical examination and breast imaging (mammography and ultrasound) for evaluation of palpable abnormalities.
- MOH and regional health authorities should continue public awareness campaigns and should hold doctors and other health care providers responsible for correctly performing CBE as a standard part of the annual physical examination for all women over age 18. Provider competence in CBE should be maintained where it has been established elsewhere.
- Efforts should continue for institutionalizing CBE in the medical school curricula.

¹² AIHA cites a Yale University clinic study showing that breast cancer patients who have primary diagnosis by mammography have better chances for survival than women diagnosed by CBE (*Reuters Health*, April 27, 2000, citing *Arch. Intern. Medicine* 2000:160:1109–15).

- The new CBE curriculum adopted by nursing schools should be used nationally for inservice refresher training of nurses.

Screening and Diagnostic Mammography

The women's wellness centers have established a systematic approach to the screening and evaluation of breast disease by adapting American College of Radiology criteria for mammography and developing pathways and guidelines for the evaluation of breast abnormalities.

Screening mammography is performed at the wellness center by a trained mammographer and technician. Active collaboration among the mammographer, the ultrasonographer, and the breast surgeon was indicated by their presence at the time of the evaluation team's visits to the various centers and their discussion of their approach to patient evaluation. In Odesa, about 3,000 mammograms have been performed by the WWC during the project time period; about 45 percent were screening (defined as lack of symptoms by the patient) and about 55 percent were diagnostic (defined as a patient with symptoms or an abnormal clinical breast examination). Most of the screening mammograms were actually performed on staff of the WWC, rather than women from the greater Odesa region. However, according to the medical team at the WWC, nonpalpable cancers were detected and appropriately evaluated and treated.

The WWC at Kyiv is the newest center to open under the AIHA initiative. It has been open only since April 1999 and has performed about 1,350 mammograms—70 percent reported to be screening and 30 percent diagnostic. Referrals come primarily from the women's polyclinic nearby.

While the Odesa Oblast Oncological Center (OOOC) agrees that screening mammograms are appropriately performed in the general setting, it also encourages screening studies to be performed at the center and strongly recommends that all women with suspected or diagnosed cancer be referred to the center for further evaluation and treatment. The OOOC, in particular, claims (without offering documentation) that not to do so results or would result in increased morbidity for the patient and a poorer outcome. However, it was evident from the interview in Odesa that some women have elected to choose the WWC for their surgical treatment based on their positive experience earlier at the WWC and previous negative experience with relatives or friends at the OOOC. This situation leads to potential competition (which is not necessarily bad) between the OOOC and the general hospital for the provision of screening, evaluation, and initial treatment services for breast cancer.

Diagnostic mammography and ultrasound at the WWC in Odesa also aid in the identification of breast abnormalities not suspicious for cancer, allowing them to be followed and biopsied as indicated by appropriate guidelines and pathways. Odesa General Hospital's approach of following benign breast disease is reported to be at variance with the approach at the OOOC, where surgical treatment is reportedly routine.

In Chernihiv, the oncological center has undertaken a mammography screening program employing single view screening films, and coordinates the screening and evaluation of the breast with a multidisciplinary team, which includes strong participation of the pathologist.

The importance of screening has entered the mindset of many healthy women in project communities and increased the number of women both with symptoms and without symptoms coming to a mammography facility for screening and diagnosis.

Both USAID-supported activities have facilitated access to breast screening and evaluation centers for breast imaging and diagnosis (mammography, ultrasound, and fine needle aspiration or core biopsy).

Downstaging

While it is too soon to expect statistics confirming the downstaging of breast cancer in the project areas—from stages III and IV to I and II—current data suggest that such results should be forthcoming soon. International experience indicates that statistical evidence of downstaging of cancer following initiation of a mammography screening program requires several years of implementation. It is too soon in Ukraine to expect such firm evidence. However, elements are in place that indicate that such downstaging may be observed in the near future. An impact indicator of the PATH and AIHA projects is the number of tumors being diagnosed at 1 cm or less. An increase in the number of small breast tumors detected under 1 cm is associated with a higher proportion of earlier stage breast cancer. Tumors are increasingly being detected at 1 cm and less in the project areas and data are mounting. The current data support the existence of this trend. However, current procedures for the collection and analysis of data are not adequate to determine accurately the existence and magnitude of downstaging that may occur.

Accurately documenting downstaging requires accurate and timely submission of information from local cancer registries to the national cancer registry. It would be desirable for mammography centers to keep track of their own data using, for example, the database developed in Chernihiv to produce information for quality assurance monitoring. A mammography database could demonstrate downstaging at the single hospital, however, but does not extrapolate to the oblast or country; only the national cancer registry can do this. PATH has assisted the Chernihiv Oblast Oncological Center and national cancer registry in achieving such capacity.

The Chernihiv pathologist who reported the following statistics offered evidence that gains have been made:

Before PATH Initiative (1997- 98):

- Ductal carcinoma in situ (DCIS) diagnosed in less than 2 percent of cases
- Stage II breast cancers, about 45 percent
- Tumors less than 1 cm, about 2 percent

After PATH Initiative (1998- 99):

- DCIS diagnosed in 8.5 percent of cases
- Stage II breast cancers, about 58 percent
- Tumors less than 1 cm, about 8.8 percent

Although not subject to statistical analysis, the discovery of noninvasive cancers (DCIS), an increase in the proportion of stage II breast cancers, and an increase in the proportion of small tumors (less than 1 cm) diagnosed, accompanied by the appearance of breast-conserving treatment approaches, all reflect intermediate gains in breast cancer control.

As a result of these and related efforts of both activities, screening mammography is now accessible to women in project areas. Mammography is now a standardized technique in project institutions and demand for this technology in other oblasts seems to be growing. Many in the general public have learned about the value of early detection of breast cancer, including the role of mammography, from the public awareness efforts of both activities. As a result, there appears to be an increased number of women with and without symptoms coming for clinical evaluation and screening or diagnostic mammography.

In all sites, project partner institutions are now finding impalpable breast cancers through mammography. Finding smaller breast cancers is associated with achieving a greater proportion of earlier stage breast cancers (i.e., reducing the proportion of women who discover they have breast cancer only when it is at an advanced stage).

There have been too few years of project implementation to expect statistically significant data on downstaging (proportion of breast cancers shifting from stage III and IV to stage I and II), but elements are now in place so that measurable downstaging can be expected in coming years. Indeed, preliminary data suggest a beginning trend toward downstaging.

AIHA presents such evidence in the following table, from AIHA's partner institution, the Odesa Oblast General Hospital with its WWC. It should be pointed out that the total number of women with stage I cancer is very small, and that there is some overlap in case categorization. Therefore, the findings should be regarded as preliminary and not definitive. (The following information was provided by the director of the hospital.)

Odesa Women's Wellness Center

Revealed (by stages)	1998	1999	2000
Stage I	13.8%	29.7%	28.1%
Stage II	41.8%	30.7%	46.9%
Stage III	34.5%	33.7%	21.9%
Stage IV	10.3%	5.9%	3.1%
Total number	29	101	32

The Dilemma of Refurbished Equipment

Refurbished equipment offers distinct cost savings advantages in a resource poor setting—but it must function properly. The question is not just refurbished versus new. Competent technical service support must be available. The quality of the vendor, warranty, and provisions for servicing are crucial.

PATH purchased three General Electric (GE) mammography machines for its Ukraine partners: one new machine for the Kyiv Institute of Oncology and two refurbished machines (for Odesa and Chernihiv oncological centers). Refurbished machines were purchased because the cost savings allowed PATH to provide a mammography machine for each of the three partners under its original equipment budget. The refurbished machine in Odesa performed well, but Chernihiv received a machine that malfunctioned frequently during most of the PATH activity. PATH chose GE because it was the only U.S. company that assured PATH that it had service in Ukraine, but that service has been extremely poor. Servicing was performed only by a general technician who was not a specialist in mammography equipment, and this was compounded by frequent delays in servicing. The Chernihiv machine has reportedly been fixed and local service capability has been promised, but only after a considerable investment of effort by Chernihiv and PATH personnel, including a visit to GE headquarters in Paris by PATH's Seattle-based deputy project director. GE has now appointed a local distributor who also is to have service responsibility and two engineers specifically trained in mammography equipment maintenance. With the sales of additional mammography machines in Ukraine, GE is now investing more resources and upgrading its service support and capabilities.

Conclusion: The quality of all mammography has improved significantly through the provision of new state-of-the-art mammography and sonography equipment, training and emphasis on proper patient positioning, optimal use of equipment and supplies, correct reading of mammograms, and quality control. Screening mammography is now accessible to women in the PATH- and AIHA-assisted facilities and is performed at a competent level of quality. As a result, these facilities are for the first time detecting nonpalpable small breast cancers. The foundation for improving breast cancer survival through early detection has been established but the cost of expansion and sustainability is a major issue.

Recommendation: The MOH should recognize the USAID/PATH/AIHA-assisted sites as pilot sites and resource centers in a national approach to upgrade mammography facilities throughout Ukraine. MOH should work together with these sites to further develop them as Centers of Excellence in mammography, and with the Ukraine Association of Radiology for setting standards in mammography quality. At a minimum, this should include criteria for accreditation of mammography centers (accreditation standards for screening and diagnostic mammography), a referral system in place for women with suspicious or abnormal mammograms to have further evaluation and treatment for both benign and malignant breast disease, and a database that describes imaging and clinical outcomes for all screening and diagnostic mammograms obtained at the

facility. Screening should not be carried out without systems for referral being in place.

Clinical Evaluation and Diagnosis

Both PATH and AIHA have stressed the importance of a team approach to the evaluation and management of breast disease. At the Odesa WWC, for example, women referred with breast problems are seen initially by the surgeon and asymptomatic patients are seen by the nurse or obstetrician/gynecologist for screening. Women with abnormal CBE are all seen by the breast surgeon and referred for further evaluation by mammography and ultrasonography as indicated, and for a gynecological examination if not yet performed. Women without symptoms but who have abnormal mammograms are also referred to the surgeon. If FNA is possible, cytological diagnosis is obtained, and when positive, the patient is referred to both medical and radiation oncologists for further consultation. Core needle biopsies are obtained and distal metastases excluded before preoperative chemotherapy is considered. Importantly, immunocytochemistry kits were introduced by PATH to permit the pathologist to determine estrogen and progesterone receptor status either at the time of core biopsy or on the mastectomy specimen. ER testing had not been routine before the introduction of this capability and ER testing in the future may be limited, due to the unavailability of resources to purchase and replace additional kits as needed.

At other WWC sites and at the oncological centers, the standard approach to the evaluation and diagnosis of a woman with a breast problem appears to involve the surgical specialist (mammologist), the radiologist and ultrasonographer, and the pathologist. The participation of the pathologist is an important component to correlating biopsy findings with the clinical and radiological picture. This correlation is critical to differentiating malignant from benign breast disease, and permits follow up of benign changes in the breast with serial CBE and repeat mammography. Approaches to the management of benign breast disease, however, appear to vary by region, based on the biases of the oncology specialists at the local oncological center.

Conclusion: Increased diagnostic accuracy is resulting in more appropriate management of both breast cancer and benign breast disease. For breast cancer, there is increasing use of breast-conserving treatment. For benign breast disease, there is less surgery and more follow up. Increased diagnostic accuracy is due to improved quality of diagnostic mammography, ultrasound, and fine needle aspiration; increasing recognition and acceptance of the importance of quality control (including adoption of American College of Radiology standards); and increased participation of the pathologist as a member of the team.

Treatment Strategies

Although only limited interventions were attempted in the area of treatment, PATH and its partners spurred a transition from old-style radical mastectomy (removal of breast itself, breast muscles, and lymph nodes) to modern, international approaches to breast cancer treatment, including breast-conserving surgery (lumpectomy, quadrantectomy).

PATH-assisted oncological centers have attempted to improve access to multidisciplinary surgical, radiation, and chemotherapy treatment for women who are suspected or proven to have breast cancer.

In the oncological centers' treatment, the clinical team (surgeon, radiation therapist, chemotherapist, and pathologist) undertakes planning. The extent of interdisciplinary discussion varied, however, with more discussion on difficult or complex cases, or if the patient was on protocol. Physician members of the team do not always discuss cases thought to be routine prospectively.

In Odesa, where a new treatment protocol was undertaken, eligible patients (predominantly stages II and III) are considered for preoperative chemotherapy, and patients with early stage disease (predominantly stage I) are considered for breast-conserving treatment. Professional education introduced by PATH at the oncological center about breast-conserving treatment and the increased involvement of the radiation therapist preoperatively as a consequence of this education resulted in a substantial increase in breast-conserving surgery with an estimated 20–25 percent of stage I patients being treated with breast conservation. The cobalt-60 equipment, while dated, is adequate to provide disease control in the conserved breast but is associated with increased skin toxicity (i.e., burns) on the irradiated area (breast and chest wall).

The introduction and completion of a specific neoadjuvant chemotherapy protocol for the preoperative treatment of stage II and III breast cancer with chemotherapy demonstrated the ability of the treatment team at the Odesa Oblast Oncological Center to develop a multidisciplinary approach to treatment of a specified condition, to adhere to the agreed-upon course of care, and to introduce the concept of written, informed consent as a basis for treating the patient. The concept of signed, written informed consent by the patient to a specified investigational treatment protocol was unprecedented in Ukraine before the introduction of this protocol by PATH at the Odesa Oblast Oncological Center. The neoadjuvant, preoperative chemotherapy protocol was presented to eligible patients with stage II or III disease, and after explaining the treatment plan and its potential benefits and side effects, the chemotherapist obtained written, informed consent. Patients who agreed to receive preoperative chemotherapy were scheduled to receive four cycles of standard and available Adriamycin and Cytosan at standard doses. Chemotherapy drugs are prepared by chemotherapy nurses gowned with masks and gloves but without the benefit of an exhaust hood to maximize protection from an aerosolized drug. Toxicity experienced by the patient was less than feared, although the doses (while standard by U.S. criteria) were higher than customary; patients benefited from brochures explaining the treatment and side effects.

Patients responding to treatment (16 of the 30 enrolled in the protocol) that agreed to complete the chemotherapy were then scheduled for mastectomy; however, at least one woman refused mastectomy because her tumor disappeared after chemotherapy. Treatment after chemotherapy was not dictated by the protocol but planned as clinically indicated by either the results of the mastectomy (histology characteristics, grade, and ER

status), patient, and/or provider preference. Tamoxifen is recommended for patients with estrogen receptor positive tumors. Chemotherapy drugs, intravenous sets, and anti-nausea drugs were provided by PATH to the participating patients.

The Chernihiv Oblast Oncological Center (COOC), in contrast, did not participate in the neoadjuvant chemotherapy protocol and the role of the chemotherapist was not as active as it was at the Odesa Oblast Oncological Center. Moreover, since surgeons administer chemotherapy at the COOC, the incentives for the chemotherapist appear to be limited by comparison.

Early Stage Disease

In PATH focal sites (Odesa and Chernihiv), increased numbers of cases are being treated with breast conservation (10–20 percent). The increased use of breast-conserving procedures reflects both the detection of earlier stage disease and the willingness of surgeons to perform breast-conserving surgery on stage I cancers.

Advanced Stage Disease

Neoadjuvant chemotherapy (chemotherapy administered before surgery) has been introduced and offers the possibility of breast-conserving surgery for stage II breast cancers and more effective palliation for stage III cancers.

Conclusion: Improvements in breast cancer mortality require both advances in early detection and effective treatment of early stage disease. One marker of more effective therapy is the appearance of breast-conserving treatment for small breast cancers. Implementing partners have spurred a transition from old-style radical mastectomy (removal of breast, breast muscles, and lymph nodes) to a breast-conserving technique (lumpectomy or quadrantectomy) in early stage breast cancer.

Clinical Team Approach

Both the PATH project and the AIHA initiative helped health professionals in all partner institutions make significant, although uneven, improvements in the team approach to clinical evaluation. Although informants who serve on these teams differed in how they characterized the pre-project situation, clinical evaluation teams typically consisted of three specialists: a surgeon, a radiologist, and a chemotherapist. A team approach, if it was used at all, was reserved only for ambiguous, complicated cases. The surgeon typically made all or almost all decisions because with later stage cancers and the prevailing practice of radical mastectomy, there was little use for input from nonsurgeons.

With improvements in early detection and indeed along the whole continuum of breast cancer care, the contributions of the pathologist, radiologist, and chemotherapist have become far more important to achieve better diagnoses and improved treatment

outcomes. There is evidence that the pathologist was not even part of a diagnostic or treatment team before the projects and before training in, for example, immunocytochemistry. Pathology was described as a low-valued specialty that was largely confined to postmortems. Now, pathologists are important members of the team, at least in several partner hospitals.

A major goal of PATH at the oncological centers was to encourage team collaboration in the treatment of patients with breast cancer. Two specific initiatives that encouraged this outcome were the introduction of ER testing kits for the pathologist and the neoadjuvant chemotherapy protocol at the Odesa Oblast Oncological Center.

The role of the pathologist is enhanced on the team by the contribution of pathology results from core biopsy specimens, which describe the histology characteristics of the tumor and the tumor's hormone receptor status.

In Odesa, the positive outcomes from preoperative chemotherapy to shrink stage II and III breast cancer before surgery resulted in increased stature for the chemotherapist as an important member of the primary treatment team for breast cancer heretofore directed in large part solely by the surgeon. Similarly, the introduction of breast-conserving treatment strategies enhanced the role of the radiation therapist as a member of the same team.

The team concept, therefore, is reinforced when each member of the team makes an important contribution to the successful treatment of the patient. Conversely, it is threatened when one or more members are no longer able to contribute their component (e.g., if ICC testing is unavailable) or if one member believes the other members are unnecessary for achieving a satisfactory outcome (e.g., at Chernihiv, when the surgeon is permitted to administer chemotherapy, the role of the chemotherapist is devalued compared with the other specialists).

It may be expected that this team approach will continue in those institutions in which it has been adopted. It is difficult to say how far beyond these institutions it will spread, or whether this approach will be taught in medical schools. This may depend on how widespread and effective early detection of breast cancer becomes in Ukraine, since significant diagnostic contributions by nonsurgeons depend, to some extent, on finding early stage cancers.

Conclusion: PATH and AIHA activities have resulted in strong diagnostic teams (surgeon, mammographer, ultrasonographer, and pathologist) in most participating sites. The team approach contributes to both improved diagnosis and treatment.

Sustainability of Innovations in Service Delivery

Sustainability of the Team Approach

The improved diagnostic and treatment team approach and the establishment of treatment protocols are expected to continue beyond USAID/PATH/AIHA assistance in partner institutions where technical assistance was focused. One reason for this assumption is that once health specialists work together as a team, they and their colleagues tend to appreciate the advantages of this approach.

It is difficult to say how far beyond the partner institutions the approach will spread or whether this approach will be taught in medical schools. This may depend on how widespread and effective early detection of breast cancer becomes in Ukraine. It may also depend to some degree on market forces.

As the transitional health care system of Ukraine becomes more influenced by market forces, the growing albeit unofficial system of patients paying for aspects of health care might help sustain the team approach. If this approach improves the likelihood of a positive treatment outcome (cancer remission, more breast conservation) and patients are treated better (more informative and honest communication from providers, less fear and anxiety, more feeling of having some degree of control over circumstances), then patients should favor opting for treatment at hospitals that provide the enhanced team approach. Health providers are motivated to want to satisfy patients in the ways just described because they earn part of their income from the number of patients they treat and treating patients successfully enhances physician reputation and leads to more patients.

PATH also developed limited capability and procedures for radiotherapy, specifically in focused-beam radiotherapy. This allows more focused treatment on cancerous tissue while leaving surrounding areas less affected. PATH produced one report on radiology quality and safety, along with recommendations.

Sustainability of Treatment Strategies

AIHA did not intervene in the treatment area, except to treat benign tumors. This is because AIHA partners are in general hospitals, where breast cancer surgery is not normally performed. Still, AIHA supported an early training visit to U.S. partner institutions for WWC health professionals and designated trainers to “improve diagnostics and treatment skills.”

For its part, PATH seems to have invested fewer intervention efforts in treatment than in other areas of the service continuum, therefore less lasting impact may be expected. Furthermore, it found more resistance to change in the treatment area. The aim and probable impact has been to reduce reliance on and frequency of radical mastectomy and to increase breast-conserving surgery (which is reported by the participating facilities). This shift is dependent upon improved early detection, which in turn depends upon improved screening (CBE and mammography, perhaps aided by BSE).

With regard to sustainability in the area of chemotherapy, PATH deliberately did not introduce new chemotherapy drugs. Instead, it found better ways for Ukrainian doctors to use existing, locally produced drugs. The new treatment protocols seem to have the potential to have effects beyond breast cancer to other cancers and even other diseases.

It was never PATH's intent, however, to introduce neoadjuvant chemotherapy as a routine. Rather, PATH's objectives were to give its Ukrainian partners the scientific experience of following a strict clinical protocol and to give them patient management and clinical experience in using the protocol and learning to use higher dosage levels that they previously feared, and learning they could do so without negative consequences. There have been several positive results. The Odesa Oblast Oncological Center team established the capacity to do rigorous clinical trials and has since been asked by two pharmaceutical companies to carry out clinical trials for other therapeutic agents, thus obtaining experience with other therapies and also providing patients with access to treatment that otherwise would not be available.

Recommendations

- Breast cancer treatment should be monitored by the regional and national cancer registries. (Accurate recording of diagnosis, stage, and treatment is the only way to monitor changes in treatment patterns and, ultimately, changes in survival associated with the effective treatment of early stage disease.)
- Professional education initiatives should establish that modern approaches to breast cancer treatment require a multidisciplinary approach, which involves each of the treating specialties in surgery, radiation therapy, and chemotherapy.

Sustainability of Diagnostic Mammography

Mammography was used in Ukraine before either USAID-supported project. Ukraine, at the beginning of the PATH and AIHA activities, reportedly had some 300 mammography machines, most of them nonfunctioning, however. Those that worked were used almost exclusively for diagnosis, which tended to be crude and relatively inaccurate. Patient positioning and lack of regular recalibration through use of a phantom were among the weaknesses of mammography prior to technical assistance from PATH and AIHA.

There are significant costs associated with mammography, apart from the initial cost of mammography machines. These include costs of film and chemicals as well as of maintenance and repair. The team discussed strategies for meeting film and chemical costs with those familiar with these issues in partner institutions. It was explained that patients are more willing to pay for diagnostic mammography than for screening mammography, assuming some ability to pay anything. In other words, as is known from other areas of health care, sick people are willing to pay for treatment or for a diagnostic

process closely related with treatment, but healthy (asymptomatic) people are far less willing to pay for a preventive measure.

The question arises: can charging patients a fee for service recover enough of mammography's costs to sustain this technology in the years to come? PATH seems unsure whether Ukraine, at least its public sector, can afford to sustain mammography at Ukraine's current level of economic development. PATH also questions how much national impact the few machines donated by PATH and AIHA in four cities have had and will have. There are 28–30 modern mammography machines in Ukraine, but they are centered in a few cities (e.g., Kyiv has 10 and Odesa has 3); some oblasts have none.

However, this overall number is already growing. Some oblasts, other than the four assisted by USAID (e.g., Ludsk) as well as at least one private clinic, are said to have ordered mammography equipment (from General Electric) with their own funds. One institution supported by PATH, Chernihiv Oblast Oncological Center, received a Siemens mammography machine in 1996, prior to PATH project assistance. If the MOH and oblast-level governmental agencies recognized the value of mammography before it was upgraded by the two projects and they were willing to pay for it, this value and willingness should have increased in the past three years. Indeed, this is reflected in the orders for new mammographic equipment.

Use of mammography in the embryonic private sector seems feasible, although the status and future development of this sector is not clear. Since Ukrainians pay—albeit unofficially—for most health care and medicines at present, and since significant increases in public sector spending in health are not anticipated, it seems that some sort of fee-for-service plan will continue to develop. However, in the absence of increased public sector spending or in the growth of an alternative model, there may be an overall decrease in screening mammography.

Diagnostic mammography, supported by the fee-for-service approach by those who can afford it, may grow as its value in early detection—and therefore in improving treatment outcomes—is demonstrated to Ukrainian doctors and patients alike. In the words of a radiologist in Chernihiv, “Mammography won't die. Our doctors have had a taste of good mammography. We had mammography before but it was crude, and we were not trained in its proper use.”

Both PATH and AIHA have developed and now leave behind a curriculum on mammography, one that includes new procedures, such as patient positioning, breast marking, and breast physiology. PATH has trained mammographers from the AIHA-assisted Left Bank hospital in Kyiv, and PATH partners participated in the quality control training workshops held by AIHA—examples of cooperation between the two USAID-assisted programs.

In sum, it may be more useful to think of the sustainability of mammography in Ukraine, rather than in the public sector. PATH and AIHA have helped establish and equip what can be thought of as national resource centers. Mammography in these centers can serve

to demonstrate and disseminate high-quality screening and diagnosis in breast cancer. The adoption of mammography in oblasts that currently lack it, as well as in the private sector, depend on economic factors and systemic reforms that are impossible to predict with assurance at this time.

Rehabilitation

Previously, relatively little was done to assist women in their postsurgical coping with the disease. Some instruction in management of lymphedema and range-of-motion was given but little in the way of psychological support. According to governmental legislation, prostheses are to be provided for all women who undergo mastectomies. However, this generally does not happen because of the hospitals' lack of financing.

PATH has devoted some attention to rehabilitation. It has

- provided a small amount of training in lymphedema avoidance,
- developed patient educational information on lymphedema and chemotherapy,
- linked chemotherapists (oncologists) from partner hospitals with relevant information available on the Internet, and
- linked local clinicians with counterparts in the United States and Poland.

C. OTHER SUPPORT MEASURES

The Breast Cancer Survivors' Movement

As demonstrated in many countries around the world, support groups are powerful tools that many patients find essential in coping with cancer. When USAID breast cancer support activities began in 1997, such networks did not exist in Ukraine, with the exception of two fledgling groups in Kyiv and Lviv. These groups, however, were not aware of each other, nor did they have contact with any of the breast cancer support groups outside Ukraine.

Today, thanks to facilitation and leadership from PATH, a vigorous breast cancer survivors' movement has arisen in Ukraine, spurred by local survivor groups that have emerged in Kyiv, Chernihiv, Lviv, and Zhytomyr. These survivor groups are beginning to serve three important functions:

1. All provide mutual support to the participating breast cancer survivors, facilitating the sharing of information and bolstering courage and self-esteem.
2. All are advocating for more effective breast cancer support (e.g., for better measures for early detection, for more respect and candor from the medical community, and for the prostheses that the government is supposed to provide).

3. Two of the groups are providing in-hospital counseling and support to patients going through treatment.

In Chernihiv in particular, the survivor group is supported and their contribution valued by the visionary director of the COOC.

PATH has played a major role in fostering the development of breast cancer survivor groups. It has done this by providing them with information, psychosocial support, and opportunities to meet other survivors from throughout Ukraine as well as from neighboring countries and the United States.¹³ PATH's work in encouraging peer support for breast cancer survivors has evoked a very positive response. PATH considers this one of the most important areas of effort that it believes will be sustained as a result of its own momentum. Contributions by PATH include

- providing leadership to develop and support community-based peer support groups for breast cancer survivors in Kyiv, Chernihiv, Lviv, Zhytomyr, as well as in other oblasts;
- providing assistance to help these breast cancer survivor groups establish peer support volunteer programs and providing training to enable them to provide emotional support and information to women hospitalized for breast cancer treatment (from counseling on postoperative lymphedema and range-of-motion to prostheses, sexual relations with husband after mastectomy, and believing that life after cancer is worth living); two groups (in Kyiv and Chernihiv) are now actively implementing peer support volunteer programs in their local oncological centers, with strong support from providers and hospital administrators;
- organizing informational exchanges and visits between breast cancer survivors in Ukraine and counterparts in Poland, Russia, and the United States;
- encouraging breast cancer survivors to speak publicly about their illness (such as at the PATH-sponsored National Breast Cancer Summation Conference convened in November 1999) in an effort to break the stigma surrounding it; and
- organizing training to support and develop survivor groups:
 - seminars for survivors in Kyiv and Chernihiv (May 1999),
 - peer psychosocial support training in Chernihiv and Kyiv (September 1999),

¹³PATH raised supplemental funding from non-USAID sources to support this.

- Ukrainian health workers and survivors visit Warsaw (October 1999),
- psychosocial support volunteer training in three oblasts (January–March 2000), and
- Ukrainian survivors’ visit to Amazonka Federation of Poland (planned for September 2000).

As a culmination of these efforts, PATH convened a 3–day Kyiv symposium on breast cancer psychosocial support (May 19–21, 2000) for Ukrainian breast cancer survivors and medical and psychological professionals involved in supporting them. This was the first such national gathering. Approximately 60 survivors from 8 oblasts participated. Also attending were survivors and support professionals from Poland, Russia, Belarus, Belgium, and the United States, including a representative from the U.S. National Breast Cancer Coalition. The following objectives were achieved by the symposium:

1. To enhance knowledge and skills, especially among survivors, regarding psychosocial care, organization of survivor groups, and implementation of specific activities.
2. To facilitate sharing of experiences, strategies, and future plans among survivors throughout Ukraine as well as among selected participants from neighboring countries.
3. To help solidify a nationwide as well as regionwide network of breast cancer survivors (individuals and groups) and medical and psychology professionals.
4. To enable leaders of the existing Ukrainian groups to meet with representatives from the Polish, Russian, and American breast cancer survivor organizations to discuss strategies for establishing a Ukrainian national coalition and for continuing regional and international collaboration and communication.

Comments from group members regarding the support value of the groups were recorded in interviews by the evaluation team. These eloquently express the value of such groups in the survivors’ own words:

I learned how to love and respect myself ...Strangely, this disease has given me a new life, good friends. We trust each other...we can talk about our secrets, even things we don’t tell our husbands or best friends.

By nature I am strong but when I heard I had breast cancer, I had an operation a week later. I was pessimistic, I rejected chemotherapy...but I was unsure about this. I thank God the group found me. I am strong again. I lead a full life now.

Svetlana [PATH consultant psychologist] recruited me. I had three operations. I was deeply depressed—I nearly gave up. I didn’t feel like a woman. After joining, I am the same woman as I was before—strong, not a sad or a dead woman. My attitude changed completely. Now life is

precious. I realized time is very limited. I want to live, I want to accomplish a lot. The quality of my life is now so important. We (in the support group) want to help others not to suffer as we did. After every group meeting, I become in a perfect mood. My husband is glad I attend because he sees how it transforms my attitude and mood.

Sustainability

Some survivor groups established during the PATH project are now registered NGOs. PATH staff raised more than \$16,000 in the Seattle area on the basis of personal appeals to friends and colleagues, which PATH distributed to the survivor groups at the closing of its May 2000 meeting. It seems useful to distinguish the support and advocacy functions of such groups. There can be support groups that lack funds but that can nevertheless be of great psychosocial value to members. Advocacy is also important and it is usually necessary to have funds to do this in a way that will have impact. The survivors also identify support activities for which it is useful or essential to have funds: maintaining a telephone hotline and a place to meet and helping those with no money to pay for cancer treatment and prostheses and helping orphaned children of group members who die.

Conclusion: Breast cancer survivor groups are an important new phenomenon related to the recent emphases on public awareness, patient education, and psychosocial support. Now registering as NGOs and considering a national coalition, these local groups provide mutual support and practical and coping assistance to women recently hospitalized for breast cancer. They will almost certainly be a primary force in advocacy for sustaining current improvements in breast cancer care and for citizen engagement in their own well-being. The survivor groups will very likely become a positive model of self-help in health care as they become more vocal and articulate.

Recommendation: The MOH and breast cancer professionals should recognize these groups as partners in breast cancer program and policy development and continue to involve them as PATH did in its November 1999 summation conference.

Infrastructure Strengthening: The Cancer Registry

An important strategy pursued by PATH was to improve the tracking and monitoring of cancer cases through process improvement in the regional and national cancer registries. Integral to this effort is the ability to prepare at the local level and transfer to the national registry accurate reports of cases, which include demographic as well as appropriate clinical information, such as pathologic diagnosis, TNM stage (international standard for describing the extent of the primary tumor, a description of the lymph node involvement, and the presence or absence of distal metastases), initial therapy, and survivor status. PATH worked with the Ukrainian Cancer Registry to support consistent use of TNM staging criteria and to improve the accuracy of cancer information. PATH assisted through the purchase of computers, software, training of both clinical and registry personnel, and support of the national registry to reinforce and continue training efforts.

A key result has been an increase between 1997 and 1998 of the proportion of cases reported with morphology noted, localization noted, ICD-9 diagnostic codes noted, TNM noted, and full date of birth noted.¹⁴

However, it is also clear that not all personnel involved appreciate this effort. For example, interviews with the registry leadership at Odesa Oblast Oncological Center indicate that he does not believe in the value of this effort, nor does he endorse the efforts of the PATH project to upgrade the registry, or to seek to increase utilization of screening and evaluation services for breast cancer. He continued by describing the Soviet style of public health, where the citizen is required to have a physical examination once or twice a year as the preferred strategy to enroll women in screening programs. Careful questioning of others (including the physician instructor in CBE at the nursing school, breast cancer survivors, and healthy women), however, confirm that the Soviet system did not include regular CBE as part of the routine physical examination. Only if a woman had a breast complaint would she be referred to the oncological center for further evaluation. The view that government needed to be more involved in developing priorities and policies toward the breast cancer problem was echoed by the oncology director in Odesa, who argued for more “oblast resources,” including a mobile mammography unit.

Chernihiv Oblast Oncological Center, with PATH support, has also introduced a mammography database (although currently only one doctor is able to use it).

¹⁴PATH Quarterly Report, April 26, 2000.

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ANNEX A
METHODOLOGY

METHODOLOGY

Objectives of the Evaluation

The scope of work specified the following objectives for this evaluation:

Conduct a participatory evaluation, using rapid appraisal, which will involve all major stakeholders, including project staff with the United States Agency for International Development (USAID), the Program for Appropriate Technology in Health (PATH), and the American International Health Alliance (AIHA), as well as the Ministry of Health, key medical institutions, practitioners, and customers/breast cancer patients. Such a participatory evaluation will be conducted by interviewing representatives of key stakeholders and facilitating small working group sessions involving stakeholders in Kyiv, Chernihiv, and Odesa. As the main result, the evaluation will provide key stakeholders with an analysis of the breast care services, effectiveness of the interventions implemented under the breast cancer programs, constraints to their further expansion, and possible approaches to needed system changes, which will be revealed and discussed during the evaluation process.

The priority of a participatory evaluation was to be on sustainability and the future. It was *not* a goal to evaluate and/or compare the two activities and approaches. USAID/Kyiv specified a participatory methodology to enable key stakeholders to have greater ownership of the findings and to facilitate follow-up actions. As such, the evaluation is considered to be a development tool for furthering the expansion of effective interventions and bolstering reforms and policy changes in the breast cancer field to be undertaken by the Ukraine Ministry of Health (MOH) and regional (oblast) leadership.

Stakeholders

The stakeholders include breast cancer survivors; women in the general population, including nongovernmental organizations (NGOs) active in women's health; the Ukraine MOH; Ukrainian counterpart organizations; USAID/Kyiv; USAID/Washington, Bureau for Europe and Eurasia, Office of Environment, Energy and Social Transition, Health Reform and Humanitarian Assistance (USAID/W/EE/EEST/HRHA), PATH, AIHA, and others.

Audience

During the participatory planning and training meeting (May 16, 2000), team members further specified that findings would be important for the following audiences:

- USAID/Kyiv, USAID in many other countries, and USAID/W (EE/EEST/HRHA and the Bureau for Global Programs, Field Support and Research, Center for Population, Health and Nutrition [G/PHN]);

- The U.S. Congress;
- Ukrainian counterpart organizations:
 - MOH: National Program on Women’s Health, Maternity and Child Care Department, and Adult Care Department; and Educational Department (responsible for preservice and post-graduate education of doctors and nurses);
 - All other institutions responsible for reducing from late (3rd and 4th stage) detection:
 - Oncology system (including the Institute of Oncology),
 - Primary care system (nurses and others),
 - Academy for Post-Graduate Medical Continuing Education,
 - Anti-Cancer Commission,
 - At the regional level: Chief Health Administrator;
- Countries in the New Independent States (NIS) interested in improving breast cancer control;
- AIHA (women’s wellness centers in Ukraine but also in other NIS countries);
- PATH;
- Commercial medical centers;¹⁵
- NGOs (many women’s NGOs [Ukraine and international] are interested in obtaining information); and
- Private companies providing equipment (e.g., General Electric, which provides x-ray products and services).

Participatory Evaluation: Background and Philosophy

Most USAID–funded projects over the years have been evaluated at midterm and in the final phases by an evaluation process variously described as objective, outside, expert driven, or external. This type of evaluation has several limitations. It is never as objective as it is assumed to be; it is often seen as adversarial towards those being evaluated, it takes time and resources away from the program’s implementation, and it often has little impact because evaluation reports typically are read by only a few people. USAID and the World Bank are among donor organizations that have in recent years actually quantified how little impact external evaluations have had. Furthermore, outsiders can

¹⁵ Commercial medical centers receive women eager to pay for screening; they also have money to buy equipment, but need the structure and guidance on how to use it properly. Some Ukrainian women now go to Paris for mammography, paying about US \$500; they would prefer not to leave the country but want comfortable conditions.

never know nearly as much about a project and the exigencies of implementation as those involved in implementation.

Another type of evaluation has been gaining favor as an alternative. The basic purpose of a participatory evaluation is to develop among all stakeholders a sense of ownership of the evaluation findings and motivate them to follow up on the implications and recommendations that flow from these.

Participatory evaluations are particularly useful in understanding *process*, which means they may be especially useful at midterm. If all stakeholders can agree on the lessons learned, constraints, and how to improve various aspects of implementation, then improvements can be made. Participatory evaluation is thus an appropriate method for fostering early adoption and early ownership of the technical assistance process and its outcomes. Participatory evaluation is also useful at the end of a project, since it provides an opportunity for the donor and all stakeholders to look thoroughly at achievements likely to be sustainable in the long term, to assess next steps, and to plan a handover of all responsibility and activities to the host country.

With USAID's adoption of a managing for results approach, USAID is moving away from documenting the achievements of individual activities and toward a broader focus on the technical area addressed by assistance and its impact within the context of host country public and/or private sector development. As this type of evaluation becomes more frequent, stakeholders from the host country begin to be more involved in thinking about adopting and institutionalizing the benefits of technical assistance.

Prior to this evaluation, USAID/Kyiv had had one previous experience in participatory evaluation, although not in the health sector. USAID personnel believed that the participatory process would be useful in assessing USAID-funded breast cancer activities, since two activities (PATH's and AIHA's) had addressed the most critical issues of breast health/breast cancer care. Those two activities with their overarching objectives are coming to an end and the advances they have achieved are to be further supported by the host country. Stakeholder participation in the evaluation process was deemed to facilitate follow-on actions by the Ukrainian medical institutions, to enhance the dissemination of modern knowledge and breast health/cancer management approaches, and to build quality standards of care supported by the Ministry of Health.

Team Composition and Methodology

The scope of work for this evaluation defined the overall approach in terms of information needed and the general procedure for collecting and analyzing this information through the participation of key stakeholders. The core evaluation team included members from the United States: two professional evaluation experts and a breast cancer specialist (Drs. Pillsbury, Green, and Harper). It also included Ukrainian specialists representing various stakeholders—specifically, a medical doctor with experience in managing health programs (Dr. Galayda) who handled in-country coordination while also providing technical input as an evaluator and the USAID/Kyiv health program manager (Dr. Radziyevska) responsible for overseeing both the PATH

support and AIHA's breast health initiative. An obstetrician/gynecologist (Dr. Mastruk) with a Kyiv women's clinic under the MOH's and municipal health administration's responsibility, was aware of PATH's program objectives, having previously served as a consultant to PATH. Dr. Mastruk also represented NGO interests as the leader of a voluntary group active in advocacy for women's and breast health. A researcher in the breast cancer domain (Dr. Novitchenko) with the Scientific Institute of Oncological Problems under the Ukraine Academy of Medical Sciences was acquainted with AIHA's activities as a part-time consultant. PATH's Kyiv-based breast cancer program manager and medical doctor (Dr. Gamazina) provided needed dimensions to the evaluation process. The evaluation team was periodically joined by other USAID/Kyiv staff to form an 8-member team for all interview sessions. A support team consisted of Ukraine-based translators, one for each pilot site.

The evaluation comprised four major phases: (1) initial interviews, document review, and preparation of the work plan; (2) stakeholder meetings, a training workshop for the evaluation team, and development of interview guides; (3) fieldwork by the evaluation team, including interviews with program stakeholders, onsite observation and data collection, and preliminary analysis in the field; and (4) final evaluation workshops to achieve consensus on evaluation findings and possible future directions, preparation of the draft final report, and review and revision of the final report.

The team met with USAID staff and other stakeholders. It visited PATH and AIHA sites in Odessa, Kyiv, and Chernihiv, and interviewed administrators, physicians, nurses, faculty, technical support staff, patients, survivors, women representing the NGO support movement, and project staff at each site. The team also met with members from AIHA's Lviv site while the latter were attending conferences in Kyiv.

Conference Participation

The team participated in conferences in Kyiv that took place during the evaluation. These were: (1) Psychosocial Support Services and Breast Cancer Survivorship (PATH-sponsored), (2) a breast health care case study review workshop (AIHA-sponsored), (3) a conference of Ukrainian radiologists, and (4) the breast cancer portion of the NIS Regional Oncology Conference.

From these efforts, the team was able to collect sufficient information to summarize findings on the continuum of activities aimed at improving breast cancer outcomes and analyze results for women in Ukraine. The approach resulted in basic agreement among the entire evaluation team on the findings, conclusions, and recommendations for follow-on activities. The approach also stressed combining and sharing all collected evaluation information and relied on participatory development of conclusions and recommendations. The process in Ukraine took place from May 11–June 2, followed by completion of the report in the United States.

Lessons Learned

This was a learning process for all involved, not only regarding the content of breast cancer support in Ukraine, but also regarding participatory evaluation itself. Because USAID seeks to increase the use of participatory evaluation, it is important to analyze procedural lessons learned from the present effort, especially ways in which it was not possible to meet the planned ideal.

1. Active participation by stakeholders is central to the participatory evaluation, both to provide the necessary depth and comprehensive perspective and to create a learning experience for the evaluation participants that will be useful in their involvement in future program planning and implementation. There was indeed active participation from stakeholders. Participant-evaluators with indepth knowledge of relevant programs were able to ask detailed questions and interpret and analyze the information obtained within a proper frame of reference. The U.S. team members were pleased with the experience and dedication of the Ukrainian team members, although it was not possible for all of them to participate in the evaluation full time. Both PATH and AIHA had various activities scheduled during the time of evaluation and other regular duties prevented full participation by some of the Ukrainian members. The scheduling of program activities (e.g., the conferences listed above) was discussed with USAID in advance; it was agreed that the timing of the evaluation coincide with these activities to provide an opportunity for the evaluation team to observe an actual program implementation, interview additional stakeholder representatives, have group sessions, and clarify sustainability issues. This approach had previously worked well for external evaluations. In the reality of the participatory evaluation, some Ukrainian team members—USAID and program staffers—were torn between their normal work and participating in the evaluation, despite their willingness to be full-time participants.
2. To reduce differences in the interviewing and analysis phases, more time is necessary for planning and training for all team members to ensure that all parties have reached the appropriate level of competence: medical specialists in evaluation and interview techniques, evaluation specialists in specific technical (medical) areas, and external team members in the in-country general context and specific program interventions and issues.
3. Even being fully aware of the participatory nature of the evaluation and willing to devote their staffs' time, the program implementing partners might treat the participatory evaluation as if it were the usual external evaluation if sufficient funding is not allocated within the program or added on for participatory evaluation. It might also be difficult for specialists representing host country stakeholders to be away from their regular duties and to stay with the evaluation full time for the extended period (3–5 weeks). Sufficient compensation could provide an incentive for making various arrangements (e.g., using annual leave) but it might not work for the necessary number of qualified specialists.

4. Active participation by stakeholders in a participatory evaluation greatly depends on funding, their participation in program development and implementation, and their awareness of overarching objectives. This ensures stakeholders' ownership of the positive results achieved, lessons learned, and even failures. The participatory evaluation could bolster the spread of experience gained and energize follow-on activities.
5. The broad participation of stakeholders did add important dimensions to the evaluation. However, the search for consensus within a participatory evaluation team (in order to facilitate ownership and/or not to insult any of the parties) may push both findings and recommendations to a certain level of generality. More controversial observations may not receive the attention warranted and recommendations may not clearly indicate the best approach for the host country to follow.
6. The involvement of participants such as USAID implementing partners' representatives who have a stake in the outcome of the evaluation (looking to find successful outcomes) can influence the process of data collection and interpretation. The tendency was to confirm programmatic rationale and practice, rather than explore different perspectives.

Recommendations for Future Participatory Evaluations

1. Resources (human and financial) for participatory evaluation should be planned and budgeted partially within the programs at the stage of work plan development for the year when a participatory evaluation is anticipated.
2. If participatory evaluation is to involve stakeholder personnel in a full-time capacity (which costs more than part-time or token participation), perhaps there should be a financial threshold for programs, above which it is worthwhile to do participatory evaluation, and below which it is not. For example, for the evaluation of a five-year, \$25 million multiprong program, it may be worth spending \$500,000 for a participatory evaluation. In contrast, if the program to be evaluated is relatively small, then participatory evaluation with full participation by stakeholder representatives may be too costly.
3. Introduction to the nature and initial elements of participatory evaluation should be an essential element of basic program development and implementation. This means initiating interest in participatory evaluation and sustainability issues at the beginning of the program, strengthening a sense of host country ownership and building readiness for the participatory evaluation.
4. To ensure maximum stakeholder participation, the participatory evaluation process should be realistically structured in terms of time, evaluation phases, and adequate stakeholder involvement, particularly of host government representatives. Full stakeholder participation is needed at the planning stage when goals, objectives, and issues are defined, as well as for synthesizing sessions. Ideally, an adequate number of stakeholder representatives should be trained in evaluation techniques to allow

formation of several groups of participant-evaluators for collecting information on certain technical areas (activities, issues) or making visits to different implementation sites. This will provide an opportunity to simultaneously obtain data from several field sites. It might also shorten the evaluation process and the time commitment of stakeholder participants. However, providing adequate evaluation training of stakeholder participants is also important.

5. A training workshop should be conducted with the stakeholder participants. This should allow adequate time to address both evaluation principles and methods and the content of the evaluation (specifics of technical areas/subareas, environment, interested parties, and acknowledgment of the different levels of familiarity with the subject). Data collection protocols and other instruments prepared by the evaluation professionals should be reviewed and revised, if necessary, during the introductory workshop. While training in interviewing and data collection techniques, supported by the evaluators' creativity, helps prepare for the evaluation process, the ideal participatory evaluation requires sufficient training time to introduce more profound evaluation methods and to discuss issues (comparison, biases, analysis and interpretation, and debating alternatives to the existing program).
6. The evaluation teams need to work with and apply unified data collection protocols and instruments. Leaving the content of each interview entirely up to the individual team based only on the general guidelines for evaluation questions might complicate an analysis of the information collected by different teams in different program sites.
7. Introductory training in evaluation methods and a more structured approach to interviews and related materials/documentation should allow the evaluation professionals to monitor the information collection by the rest of the team members through observations of interviews, providing guidance between interviews and daily review sessions. The evaluation specialists need to provide leadership in reviewing data collected, synthesizing and analyzing findings, putting them together with recommendations into intermediate summaries, and compiling a report.
8. While it is preferable that all evaluation participants are able to equally speak and write common language, many host country stakeholders do not have adequate foreign language skills. Also, it may not be possible to find external/foreign evaluators who speak the host country language. High-quality translation services may be needed to allow adequate exchange of information between host country team members and external/foreign specialists during data collection, review sessions, analysis, and reaching agreement on conclusions and recommendations.



ANNEX B

**PRINCIPAL EVENTS AND EDUCATIONAL MATERIALS DEVELOPED BY
UKRAINE BREAST CANCER ASSISTANCE PROJECT (PATH)**



Ukraine Breast Cancer Assistance Project (PATH)

Principal Events

Event	Date	Number of Oblasts Represented
First CBE Seminar for Training of Trainers in Ukraine	November 1997	4
Kyiv Symposium on Management of the Breast Mass	April 1998	7
Conference with Ukrainian Clinicians on Psychosocial Topics	April 1998	3
ER/PR Test Training in Kyiv and Odesa for Lab Technicians	April 1998	3
Mammography Seminar and Ultrasound-Guided Biopsy Training	June 1998	12
Mammography Positioning and Quality Control Training in Kyiv and Odesa	June 1998	12
Chemotherapy Technical Assistance Consultation in Ukraine	July 1998	4
Psychosocial Support and Patient Care Training Workshops	September 1998	2
Second CBE Seminar for Training of Trainers in Ukraine	October 1998	18
Psychosocial Training Workshops Held in Chernihiv and Kyiv	February 1999	5
Odesa Breast Cancer Symposium	April 1999	17
Screening Mammography Workshop for Radiologists	June 1999	4
Peer Psychosocial Support Training in Chernihiv and Kyiv	September 1999	3
Kyiv Symposium on Breast Cancer Psychosocial Support	May 2000	12
Proposal Writing Training for the Leaders of Breast Cancer Survivor Groups	June 2000	7

Educational Materials Developed by Ukraine Breast Cancer Assistance Project (PATH)

For Medical Providers:

1. Clinical Breast Examination 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 April 1999 Conference Abstracts (Russian)
7. Clinical Breast Examination Videotape (Ukrainian)
8. Psychosocial Training Manual for Breast Cancer (Ukrainian)

For Women:

1. Ten 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)
2. Four Informational Flyers
 - a. Recommendations for Breast Self-Examination (Ukrainian)
 - b. Eighteen Steps to Prevention of Lymphedema (Ukrainian)
 - c. Information about the Lymphatic System (Ukrainian)
 - d. Infectious Lymphangitis (Ukrainian)
3. One Poster: Three Ways to Early Detection of Breast Cancer (Ukrainian)
4. One Shower Card: Make Breast Self-Exam Your Vitally Important Habit (Ukrainian)
5. Breast Self-Examination Videotape (Ukrainian)
6. Relaxation Audiotape (Ukrainian and Russian)
7. Three Television Spots (Ukrainian)
8. Breast Cancer Peer Support Volunteer Training Curriculum (Ukrainian)

ANNEX C
SCOPE OF WORK
(from USAID)

SCOPE OF WORK

(REVISED)

Participatory Evaluation Ukraine Breast Cancer Activities

I. Rationale for Modification

The modifications that are now incorporated into the new revised Scope of Work include:

1. Inclusion of AIHA as a stakeholder in the participatory evaluation in order to give them an opportunity to present results achieved under the Breast Health Initiative. AIHA's Breast Health Initiative is a substantial component of USAID technical assistance in the breast cancer field in Ukraine. The last evaluation of AIHA's activities was held in 1997, before the actual start of the breast health program. Through the participatory evaluation process, AIHA's experts will be able to share their understanding of problems/constraints to the implementation of effective interventions, their vision of the potential development in breast care.
2. Extension of this Task Order from 28-30 day to 35-40 days;
3. Service of an additional consultant is requested to conduct the participatory evaluation, and to provide in-country training for the evaluation team.

This is the rationale for this modification and additional funding.

II. Purpose

The contractor will provide an objective and participatory evaluation of the Ukraine Breast Cancer Assistance Project (CA EE-A-00-97-00003-00) implemented by the Program for Appropriate Technology in Health (PATH) and the Breast Health Initiative under the Medical Partnership Program (CA EURO-0037-A-00-4016-00) implemented by the American International Health Alliance.

The purpose of the evaluation is to assess effectiveness, identify results to date through activity/process indicators, as well as health indicators. The evaluation team will determine progress towards achieving specific objectives of both activities and Strategic Objective (SO) 3.2: Increased access, quality, efficiency and sustainability of health care. Also, the team will identify problems/constraints, if any, to the successful achievement of the activities' purposes, and consider possible future interventions in the breast cancer area within the women's/primary health care context. The evaluation will enable key stakeholders, such as the Ministry of Health and medical practitioners, as well as non-governmental breast cancer survivors support groups, to define and address issues and

questions of their own, thereby enabling them to feel ownership of the findings and to facilitate their potential follow-up actions. As such, this evaluation is to be considered as a development tool for furthering expansion of effective interventions and bolstering reforms and policy changes in the breast cancer field to be undertaken by the Ukraine Ministry of Health.

The contractor will prepare a written evaluation report for submission to the Ukraine Ministry of Health, USAID/W/EE/DGSR/HRHA, USAID/Kiev, PATH, AIHA and other stakeholders.

III. Background

The United States government is concerned about consequences of the Chernobyl power plant disaster in 1986. Through USAID, it sponsors a package of health programs to mitigate Chernobyl's aftermath. A Congressional earmark has aimed funding "to screen, diagnose, and treat victims of breast cancer associated with the 1986 incident at the Chernobyl reactor in Ukraine" (FY 1996 Appropriations Act).

Long-term follow-up of the survivors from Nagasaki and Hiroshima has demonstrated the positive correlation between acute, high-level exposure and increased incidence of breast cancer ten or more years later. The Chernobyl accident issued lower doses of radiation over a longer period of time than in Japan. While direct extrapolation from the Japanese experience may not be warranted, the typically long dormancy period for breast cancer suggests that some increase in incidences may be anticipated ten or more years after exposure, with higher incidence rates among women who were young at the time of exposure. Chernobyl constitutes not only direct irradiation as a potentially significant new risk factor of breast cancer. Female Chernobyl victims have also suffered from harsh socio-economic changes, relocation, fear for their and their family members' health, which has resulted in psychosocial tension. Psychosocial disorders may also lead to hormonal status disturbances, to changes in reproductive health and behavioral patterns, and may also be risk factors for breast cancer.

Breast cancer is the leading cancer among women in Ukraine. The Ukrainian health care system is not currently prepared to adequately address the needs of breast cancer patients. Health status in Ukraine is declining, with generally rising morbidity and mortality, as well as lowered life expectancy. The health care system's approach to breast cancer has offered inadequate screening, late detection, radical surgery, insufficient radiation therapy and/or chemotherapy, and the virtual absence of rehabilitation or counseling services. The need for system improvements is independent of any additional burden that may result from the Chernobyl disaster. The implementation of a modern, cost-effective, sustainable program in breast care is of potentially great help to victims of Chernobyl.

In 1998, a Health Strategy was prepared and approved by the USAID/Kiev Mission to strategically guide its future assistance to Ukraine in the health sector. The goal of the Strategy is to assist Ukraine in reforming primary health care, improving the capacity of health practitioners to effectively and efficiently provide community-based health

services. Well-organized cancer screening is an important component of primary health care based on prevention, early detection, and appropriate basic care. Psychosocial support adds a needed dimension to a primary health care service. As such, breast cancer activities apply to and bolster the favorable outcomes of Strategic Objective 3.2 as part of its Intermediate Result 3.2.1: Improved health care services delivery.

IV. Activities To Be Evaluated

1. Ukraine Breast Cancer Assistance Project

The Ukraine Breast Cancer Assistance Project has not been focused exclusively on women affected by Chernobyl, but on all women. In an environment where there may be a substantial under-diagnosis of breast cancer at early stages, any program which seeks to strengthen breast cancer screening and diagnosis would initially identify increased numbers of cases. Increased number of early breast cancer under a restricted program for only a population of Chernobyl victims could cause unjustifiable anxiety.

The Ukraine Breast Cancer Assistance Project was authorized between USAID and PATH on December 18, 1996 with a PACD of December 31, 1999. This USAID/PATH \$3.8 million project has sought to improve the access to and quality of breast cancer screening, diagnosis, and treatment services among women in Ukraine, with particular emphasis on those exposed to radiation from the Chernobyl accident. It has focused on enhancing the cost-effectiveness of providing breast care. PATH has requested an extension of the project at no additional cost from December 31, 1999 through September 30, 2000 that was granted.

The project has been primarily active in Kiev, Chernigov and Odesa regions (oblasts) in order to include Chernobyl victims, as well as broader Ukrainian populations. Kiev and Odesa Oblasts have the highest concentrations of breast cancer cases. The highest concentrations of female Chernobyl victims now live in Kiev, Kiev Oblast, Chernigov Oblast and Zhitomir Oblast. Odesa and Chernigov Oblast Oncological Centers, Kiev Institute of Oncology were chosen to be the initial Ukrainian partner institutions to foster collaboration between American and Ukrainian professionals.

The project emphasis has been on enhancing breast cancer services in both preventive and therapeutic care. The major actions reinforced screening modalities for early cancer detection in more treatable stages utilizing clinical and mammography breast examination. Activities have also included assistance in the standard cancer database system implementation, essential laboratory support for diagnostic work-up and patient monitoring during treatment, the pilot project on implementation of a standard U.S. chemotherapy protocol, psychological counseling.

2. AIHA's Breast Cancer Initiative

This component under the AIHA's Medical Partnership Program was developed at least in part in response to a USAID call led by Congressional directives and encouraged by

USAID through separate funding at a total level of \$2.5 million. The Breast Health Initiative was launched in 1997. The objective of the breast cancer initiative is to develop comfortable and easily accessible outpatient centers that are to provide breast cancer screening, including mammography and a full range of educational materials related to breast cancer prevention, detection, and treatment. Women with cancer are to be referred to specialized facilities for treatment. Sites chosen for the program are Women's Wellness Centers located at the Odesa Regional Hospital, Lviv Railway Hospital, and Kiev Center for Maternal and Child Care on the Left Bank. After the end of the Medical Partnership Program in spring 1998, the breast cancer activities were continued under the sustainability grant to further support Women's Wellness Centers.

IV. Overall Objectives of the Evaluation

The Contractor will:

- Conduct a participatory evaluation, using rapid appraisal, which will involve all major stakeholders, including project staff with USAID, PATH, and AIHA, as well as the Ministry of Health, key medical institutions practitioners, and customers/breast cancer patients. Such a participatory evaluation will be conducted by interviewing representatives of key stakeholders and facilitating small working group sessions involving stakeholders in Kiev, Chernigov, and Odesa. As the main result, the evaluation will provide key stakeholders with an analysis of the breast care services, effective interventions implemented under the breast cancer programs, constraints to their further expansion, and possible approaches to needed system changes which will be revealed and discussed during the evaluation process. For more information about rapid appraisal, refer to Attachment II and III – “Participatory Evaluation” and “Rapid Appraisal and Beyond”, and /or <http://cdie.usaid.gov>;
- Identify, quantify and document the outputs, the results to date, including success stories and lessons learned, and the impact of the breast cancer activities according to objectives of both programs (as stated in the Cooperative Agreement, work plans), as well as in relation to the applicable goals under Strategic Objective 3.2;
- Identify factors contributing their effectiveness, not only including current changes in performance/results, but also those institutional changes that laid the basis for future results;
- Identify potential linkages with other USAID health programs, and other international donor programs;
- Identify the potential follow-up actions to be undertaken by the Ministry of Health and national sustainability of the system changes developed and tested in pilot sites;

- Recommend the most effective strategies and potential breast cancer interventions to be pursued by USAID, building on the successes of the current programs in order to strengthen women's/primary health care service delivery in Ukraine.

V. Methods and Specific Tasks

- A. Prior to commencing field work, the contractor will prepare and submit a concise written work plan to USAID/Kiev, describing the specific activities to be undertaken, including site visits and a timeline, and indicators to be used to assess the effectiveness of the programs.
- B. A technical discussion should be included which will provide a brief overview of what is currently known about the breast cancer situation in Ukraine, as well as commentary on current breast care service delivery.
- C. In collaboration with the USAID/Kiev Mission, USAID/W/EE/DGSR/HRHA, PATH, and AIHA, the Contractor will collect and review background documents, including:
 1. The Cooperative Agreement with PATH to implement the Breast Cancer Assistance Project in Ukraine and other authorizations and/or related project identification documents, and any sub- contracts.
 2. AIHA's Breast Health Initiative identification documents, and any sub-contracts.
 3. Action plans, periodic and special reports of PATH and AIHA, their staff in Ukraine, and any sub-contractors.
- D. The contractor will conduct interviews and hold briefings with relevant staff associated with both implementing partners, and at USAID/EE and USAID/Kiev.
- E. The Contractor will develop an initial open-ended interview guide, and choose methods for gathering relevant information.
- F. The contractor will carry out fieldwork evaluation in collaboration with all stakeholders:
 - a. Identify key stakeholder groups and clarify the roles and responsibilities of their representatives in the activities, for breast care in Ukraine, and in the evaluation.
 - b. Interview Kiev-based representatives of the key stakeholder groups, e.g., PATH and AIHA staff in Ukraine, USAID/Kiev program managers, relevant Ministry of Health officials, breast care providers, including those trained under the Breast Cancer activities, breast care patients, members of the support groups and other key beneficiaries and stakeholders. The interview will enable the Contractor to

- understand better what has transpired during both activities implementation, the issues of concerns to all stakeholders, as well as to identify appropriate individuals for the evaluation team.
- c. As the result of the above described process, the Contractor will next work with major stakeholders to review the initial objectives of the evaluation, deeper analyze the efforts to date, identify key issues and informants, revise the open-ended interview guide.
 - d. Compile a 7–9 member multi-disciplinary interview team (health professionals, breast cancer experts, experts in evaluation techniques) and provide initial or short refresher training on open-ended interviewing and the rapid appraisal technique, instructions on the specifics of the Breast Cancer Project evaluation. The interview/evaluation team might include 2-3 USAID/Kiev Mission employees previously trained (e.g., for Effective Local Government project evaluation) in basic data collection and analysis, including open-ended interviewing and rapid appraisal.
 - e. Schedule and conduct site visits, including setting up interview and small working group sessions; attending previously planned workshops or conferences on the “primary focus” activities. Methods used could include semi-structured individual interviews, focus groups, surveys, etc. The methods used should emphasize explanations and assessments of the value of the project from the perspectives of the customers and other stakeholders, rather than just a quantitative assessment.
- G. The Contractor will analyze the information collected, including the development of clear and specific findings, conclusions, lessons learned and recommendations. The Contractor will facilitate a half day-one day session of the stakeholders and the interview team, beginning with the presentation of the outline of the findings. The goal of this session will be to reach clarity on the evaluation findings and conclusions. The group should also identify the areas of consensus and divergences, explaining the latter to the degree possible. Lastly, the group should suggest future efforts for improvement of USAID’s and other stakeholders’ program based on the results of the Contractor’s evaluation and the rapid appraisal team’s conclusions, as well as any other information that came out of the process.
- H. The Contractor will write the draft final report of the overall evaluation conclusions, including input from the rapid appraisal, and recommendations for possible future USAID programming which will be reviewed by key USAID/Kiev Mission staff. An initial draft of the report will be due prior to departure from Ukraine. A copy will be given to PATH and AIHA. All will be expected to provide comments on this report.
- I. After receipt of these comments, the Contractor will issue a final report. The final report is to be available within 30 days after the Contractor receives comments.

The contractor is responsible for the results of this evaluation, including any need to modify the evaluation design, which may emerge once the task order has begun. The contractor will ensure that USAID/Kiev agrees with any changes in this SOW. No

change in the overall level of effort or task order total is possible without written concurrence by the Contracting Officer.

VI. Time line

The evaluation will start in May–June 2000, depending on the availability of consultants and scheduling needs of the Mission. The entire assignment is estimated to take approximately 35-40 days. Time required for the information gathering and document review before the fieldwork will be approximately 4–6 days. At least two weeks prior to departure from the United States, the Contractor shall submit a draft work plan to USAID/Kiev project management. Once in Kiev, Ukraine, the Contractor should allow up to 6 days to interview major stakeholders and, then, adjust evaluation tools. Time required for the evaluation team training could be approximately one day. Two five-day field visits will be needed to conduct interviews, focus group etc. in Chernigov and Odesa. After the fieldwork, approximately 5-7 days will be needed to analyze outcomes of the evaluation, to conduct the session with the stakeholders to clarify conclusions and future actions, to prepare a draft final report and brief USAID staff. Upon return to the United States and receipt of USAID, AIHA and PATH's staff comments on the draft final report, the Contractor will spend three days in order to prepare a final document.

VII. Deliverables

- A. The Contractor will submit a draft work plan for the evaluation process to USAID/Kiev project management for concurrence. The contractor will be required to maintain regular contact with the USAID/Kiev during the planning and execution of the evaluation.
- B. Interview guidelines and other evaluation tools will be discussed with major stakeholders and submitted to USAID/Kiev.
- C. Upon the end of the field visits and a concluding session with major stakeholders, the Contractor will provide a debriefing to the Kiev Mission Health Team and a draft final report including the results of the rapid appraisal, the overall evaluation conclusions and recommended next steps.
- D. A final report should include an evaluation of results to date, and a synthesis of lessons learned. Also include a set of recommendations for Ukraine and the donor community, specifically based on the experience of implementing these USAID funded activities. Ten total copies of the report will be submitted to USAID/Kiev (5 copies) and USAID/W (5 copies). The final report will contain a three to five page executive summary and will not exceed 30 pages plus annexes not to exceed 30 pages.

Specifically, the report should:

1. Provide assessment of the performance set forth in the Cooperative Agreement with PATH and AIHA's Breast Health Initiative identification documents.
2. Identify results to date and /or successful interventions and accomplishments, or lack of, through activity/process indicators, as well as health indicators.

3. Evaluate the effectiveness and impact in relation to specific activity objectives and Strategic Objective (SO) 3.2.
4. Identify problems/constraints, if any, and address any issues raised by the stakeholders.
5. Consider possible strategies for major stakeholders in order to further policy/system changes or potential interventions in the area of breast cancer early detection and treatment.
6. Identify strategies which would be the most effective for USAID to pursue within the women's/primary health care context.
7. Describe the contributions that have been made to assessing the accomplishment of project objectives and to strategic planning by having involved major stakeholders in the evaluation process.

VIII. Team Composition

USAID/Kiev is requesting the services of three professional consultants to evaluate the Ukraine Breast Cancer activities, and a local administrative assistant. The lead facilitator should be experienced in the use of qualitative and participatory methods, rapid appraisal and group dynamic techniques. A health professional with expertise in breast cancer issues with medical background and primary health or international health consultant should have experience with participatory methods, or they should be open to using participatory development approaches for the evaluation work. Relevant previous USAID evaluation experience, familiarity with the region, and Russian/Ukrainian language skills are desirable. Participation of the Ukrainian parties' representatives in the evaluation process will require funding for travel within Ukraine.

The Contractor will guarantee that substitutions will not be made for individuals selected as team members without the approval of the designated SO 3.2 Health Core Team representative/Health Activity Manager, USAID/Kiev.

Throughout this process, USAID/Kiev SO 3.2 (Health) Core Team members will be involved with the evaluation process and will be members of the team.

IX. Other

- A six-day workweek is authorized for field team members as appropriate while conducting the field investigations, site visits, and interviews.
- The team will conduct its evaluation under the technical guidance of USAID/Kiev and is requested to keep the Mission fully apprised of progress. The evaluation is intended to be forward thinking, constructive and collaborative. While assuring confidentiality, the contractor is requested to keep the lines of communication open and candid.
- Budget: Provide a simple functional budget illustrating cost by proposed activity.

- Utilize existing documentation, local experts, secondary activity information, data studies, and interviews to obtain information.
- Primary audience: USAID/Kiev and major stakeholders.
- The contractor will be fully self-sufficient for all logistical or support services, such as travel, communications, translation or interpreting services, scheduling, etc. USAID officers will cooperate fully with the evaluation and assist in identifying and providing appropriate documentation. USAID officers must be given one-week advance notice regarding making available documents for review.
- The USAID Mission will furnish the following documents prior to start-up of fieldwork to assist in the evaluation process:
 - 1998 Ukraine Health Strategy
 - Strategic Objective Performance Indicators
 - Results Tree
 - PATH and AIHA background documents

ANNEX D
KEY CONTACTS

Key Contacts

USAID/Washington/EE/EEST

Mary Ann Micka, Cognizant Technical Officer

PATH: Ukraine Breast Cancer Assistance Project

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
Kristin Bedell	Project Administrator
Svitlana Okromeshko	Program Associate
Nancy Parent	Program Assistant

Ukraine Breast Cancer Team

Yekaterina Gamazina, M.D.	Project Manager
Alla Kovtun	Program Associate
Yelena Kononova	Program Associate
Svitlana Karpilovskaya	PATH Consultant Psychologist
Natalya Suprun	PATH Consultant, Psychosocial Support Activities

KYIV

Ministry of Health

Dr. Tamara Irkina	Deputy Chief, the Main Department of Maternal and Child Health and Head, Obstetric Gynecological Department
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Ukrainian Research Institute of Oncology and Radiology

Dr. Valeriy Tarutinov	Director, Ukrainian Center for the Diagnosis and Treatment of Breast Disease
Dr. Volodymyr Medvedev	Deputy Director on Radiology, Chief Ultrasound Expert for the MOH
Dr. Ihor Ponomariov	Head of Statistics Department
Dr. Lyudmila Krokhmalyova	Mammographer
Dr. Zoya Fedorenko	Chief, Organizational-Methodological Department
Dr. Liudmyla Gulak	Chief, National Cancer Registry

Kyiv City Oncological Center

Dr. Petro Oliynichenko	Chief Doctor
Dr. Vasyl' Drozdov	Chief, Mammological Department
Dr. Andriy Neyman	Surgeon/Mammologist
Dr. Lyubov Zakhartseva	Chief, Pathology Department
Dr. Tetyana Volevakhina	Chief, Rehabilitation Department

Kyiv City Diagnostic Center

Dr. Yakiv Babiy	Director, President of the Ukrainian Association of Radiologists
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Kyiv Nursing School #3

Dr. Tetyana Khokhlich	Professor
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Kyiv Breast Cancer Survivors' Group

Mrs. Svitlana Sidorenko	Breast Cancer Survivor
Mrs. Larisa Khobich	Breast Cancer Survivor
Mrs. Vera Popkova	Breast Cancer Survivor

CHERNIHIV**Chernihiv Oblast Oncological Center**

Dr. Volodymyr Zotov	Chief Doctor
Dr. Natalya Zakharchenko	Chief, Radiology Department
Dr. Yulia Zakharchenko	Radiologist
Dr. Oleh Stolenets	Surgeon–Mammologist, Chief, Mammological Department
Dr. Alla Moloshok	Chief, Pathology Department
Dr. Alla Shatalyuk	Chief, Outpatient Department
Mrs. Lidia Stolenets	Chief Nurse

Chernihiv Breast Cancer Survivors' Group

Mrs. Valentyna Gromova	Breast Cancer Survivor
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ODESA

Odesa Oblast Oncological Center

Dr. Vilen Stepula	Chief Doctor
Dr. Natalya Martsinkovskaya	Chief, Chemotherapy Department
Dr. Sergiy Bondar	Chief, Surgical Department
Dr. Andriy Suprun	Surgeon Mammologist
Dr. Georgiy Rozdorozhnyuk	Chief, Pathology Department
Dr. Larissa Polyak	Radiologist
Dr. Eugeniy Vorontsov	Radiology Technician

LVIV

Lviv Oblast Oncological Center

Dr. Yaroslav Shparyk	Chief, Chemotherapy Department
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Lviv State Medical University

Dr. Borys Bilynsky	Deputy Director
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Lviv State Medical University, Pathology Department

Dr. Dmitri Zerbino	Director
Dr. Marta Servetnyk	Chief, Immunocytochemistry Department

Lviv Amazonka Club

Mrs. Svitlana Oliynyk	Breast Cancer Survivor
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AIHA: Breast Health Initiative

ODESA

Odesa Oblast Hospital (OOH), Women's Wellness Center, Breast Health Center

Dr. Vassily Gogoulenko	Chief Doctor of the OOH
Dr. Svetlana Posokhova	Director, WWC, Deputy Chief, OOH
Dr. Alexander Berzoy	Surgeon–Oncologist–Mammologist
Dr. Irina Loginova	Radiologist–Mammographer
Dr. Viktor Soldatov	Sonographer, WWC/BHC
Dr. Vladimir Bevz	Gynecologist–Mammologist
Dr. Valentina Goloubenko	Vice Director, WWC
Mrs. Irina Zagoruiko	Radiologist Technician
Mrs. Natalia Zadvornaya	Midwife, Nurse Educator

LVIV

Lviv Railway Clinical Hospital, Women's Wellness Center

Dr. Liudmyla Gutsal	Director
Dr. Andriy Kens	Surgeon–Mammologist
Dr. Natalya Khomyn	Sonographer
Dr. Liudmyla Matsiyevska	Radiologist
Mrs. Natalya Khlopyk	Radiology Technician

KYIV

Kyiv Maternity Hospital #6, Women's Wellness Center

Dr. Lesya Yakovenko	Director
Dr. Ihor Kovalchuk	Surgeon
Dr. Svetlana Kuzmina	Radiologist
Dr. Liliya Shvets	Surgeon
Dr. Olena Yatsiuk	Radiologist
Mrs. Kateryna Yatsiuk	Nurse Educator
Mrs. Galyna Zhadan	Radiologist Technician

ANNEX E

PRINCIPAL BACKGROUND DOCUMENTS AND REFERENCES

Principal Background Documents and References

Ukraine Breast Cancer Assistance Project

I. Memorandum of Understanding between the Ukraine Ministry of Health and the Program for Appropriate Technology in Health (PATH)

II. Background Material: PATH/Breast Cancer Project

- Work plan
- Contract with the United States Agency for International Development (USAID)
- Project proposal
- PATH Ukraine Sites–General Information
- Key contact information
- Quarterly Progress Report: 10/1–12/31/99
- Quarterly Progress Report: 7/1–9/30/99
- Quarterly Progress Report: 4/1–6/30/99
- Quarterly Progress Report: 1/1–3/31/99
- Quarterly Progress Report: 10/1–12/31/98
- Quarterly Progress Report: 7/1–9/30/98
- Quarterly Progress Report: 4/1–6/30/98
- Quarterly Progress Report: 1/1–3/31/98
- Quarterly Progress Report: 10/1–12/31/97
- Quarterly Progress Report: 7/1–9/30/97
- Quarterly Progress Report: 4/1–6/30/97
- Quarterly Progress Report: 1/1–3/31/97

III. Participatory Evaluation

- Participatory Program Evaluation: A Manual from CRS
- Participatory Monitoring and Evaluation (PME) Module
- Workshop Notes: Rapid Appraisal and Beyond
- Conducting a Participatory Evaluation: Tips from USAID
- Using Rapid Appraisal Methods: Tips from USAID
- The Participation Toolkit
- Participatory Monitoring, Evaluation and Reporting (PACT)
- Participatory Program Manual (Aubel CRS)
- Participatory Evaluation: Urban Public Transportation Improvement and Effective Local Government Programs in Ukraine (Abt Associates)

References

Butler, M., et al. *Evaluation of The American Health Alliance (AIHA) Partnerships Program*. For the United States Agency for International Development. January 1988.

Organizing Committee under the Cabinet of Ministers of Ukraine. *Status of Women in Ukraine*. National Report for the Fourth World Conference on Women, 1995.