Evaluation of Key Components of PATH’s Ukraine Breast Cancer Assistance Project: Ten Years After

October 21, 2011
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Introduction

Project background
From January 1997 through September 2000, PATH implemented a $3.8 million project funded by the US Agency for International Development (USAID) to strengthen breast cancer services in selected regions of Ukraine. The Ukraine Breast Cancer Assistance Project had the following key goals:

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

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

Key interventions included the following:

- Training for health care providers (through workshops, study tours, fellowships, medical symposia, conferences, and literature dissemination), including radiologists, pathologists, surgeons, nurses, and mammography technicians.
- Provision of equipment and supplies (e.g., four mammography units, film processors, film, chemicals, accessories, one ultrasound machine, pathology equipment, surgical equipment and supplies, computers, and 30 courses of chemotherapy).
- Improving patient understanding and public awareness (e.g., development of educational materials for patients, families, and the public; development of a survivor support and outreach network through training, exchange visits, and psychosocial support by health care providers and also survivors).
- Strengthening the health infrastructure (e.g., strengthening cancer registry data management and pilot development of a regional information system to track outcomes of clinical breast exams or CBE).
- Influencing policy and practice guidelines (e.g., demonstration of an early detection strategy using both CBE and mammography and demonstration of an international standard-dose chemotherapy regimen through a clinical trial).
- Demonstration of the value of immunocytochemistry (ICC) methods for better pathology.
- Assessment of radiotherapy capacity and recommendations for improvement.
- Modification of surgical approaches to breast cancer (e.g., breast-conserving surgery for early stage disease) and benign breast disease.
Results at the close of the project

By the end of the project, progress had been made on many fronts in Chernihiv and Odesa—the oblasts or “regions” where most activities were centered—along with smaller accomplishments in Lviv and Kyiv City where fewer activities took place. In addition to providing small amounts of medical equipment including mammography and ultrasound machines, the project developed and introduced several educational curricula. Materials for patient education and public awareness were designed, produced, and distributed. By the final project meeting it was clear that attitudes among doctors and nurses in project sites had changed with regard to certain clinical practices, such as breast-conserving surgery, the importance of biomarkers, and ultrasound-guided biopsy. Also, the importance of psychosocial support for patients was recognized for the first time ever, including the need to tell patients their diagnosis, to provide counseling on treatment options, and to offer further support during treatment and follow-up. Breast cancer survivor groups, which had not existed before in Ukraine, had been established in three cities. In Odesa, the capacity to conduct rigorous clinical trials and use the results to guide patient management was established, while in Chernihiv a pilot screening program was initiated and evaluated.

In the final project report, several reasons were cited in support of the belief that many of the project’s achievements were sustainable beyond the life of the project. These included:

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

The current evaluation provides a unique opportunity to test some of those beliefs about project sustainability.

Evaluation goals and objectives

The overall goal of the evaluation was to assess, ten years after the end of the project, the long-term sustainability and impact on disease down-staging and quality of care in three focus areas of the interventions (screening, diagnosis, and recovery) that were pursued during the Ukraine Breast Cancer Assistance Project managed by PATH from 1997 to 2000. Specific objectives were to determine the extent to which:

- Tools and curricula developed by the project are still in use in each of the three project areas, for example:
• Mammography technician training
• CBE
• Psychosocial support curriculum for nurses
• Peer support curriculum for survivor group members
• Clinical/medical skills and activities are still being practiced in each of the three areas, for example:
  • CBE
  • Mammographic screening protocols
  • Ultrasound-guided needle biopsy
  • Breast-conserving surgery
  • ICC evaluation
• Registry data are maintained according to international definitions and standards.
• Equipment and supplies are adequate (quantity and functioning).
• Psychosocial support has improved during and after treatment:
  • Communication practices ensure that women are fully informed of their diagnosis and options for treatment.
  • Peer support (information, emotional support, and referral to resources) is available to recently diagnosed women.
• Policies and practices have been adopted by other regions (non-project sites).
• Outcomes have improved, through earlier detection or better survival where the project was active (compared to oblasts where PATH was not active).

Where possible, we also tried to estimate the number of women who have or may have benefited from services initiated or strengthened during the project period. Due to the limited budget available, several aspects of the project were not included in the evaluation or were assessed only anecdotally: public attitudes toward breast cancer, dissemination of modern practices into other oblasts, incorporation of teaching modules and methods into official medical and nursing curricula, chemotherapy practices, radiotherapy practices, and distribution of educational materials for patients and the general public. The evaluation focused on Chernihiv and Odesa, with some inputs obtained in Kyiv, but it was not possible to visit Lviv or include people there in the data collection.
**Methods**

The evaluation design used a qualitative approach, based primarily on in-depth personal interviews with key stakeholders during site visits and a review of policy documents, registry data, and other relevant literature. Site visits were confined to oncology hospitals where the project concentrated its activities previously: National Cancer Institute, Chernihiv and Odesa Regional (Oblast) Oncology Centers (*Dispansers*), and Kyiv City Oncology Center.

**Participants**

Interviews were conducted with 16 people from the identified sites. These included the heads of the National Cancer Institute and the regional oncology centers in Odesa and Chernihiv; heads of radiation diagnostics (including mammography) from Kyiv and Chernihiv and the head of radiation diagnostics from the Shupik Medical Academy for Postgraduate Medicine; head of pathology from Kyiv City Oncology Center; staff from the national cancer registry; head of chemotherapy from Odesa; surgeons from Odesa and Chernihiv; chief nurse from Chernihiv; psychologist from Chernihiv; and heads of survivors groups in Kyiv, Odesa, and Chernihiv. A complete list of those who contributed to the evaluation is contained in Annex 1. As this was deemed program evaluation by PATH’s Research Determination Committee, the protocol and instruments did not require review by the Research Ethics Committee.

**Data collection: interviews, documents, statistics**

A national consultant with experience in qualitative research compiled a list of interview candidates, with help from PATH staff of the original breast cancer project, based on the topics to be covered and the names of people previously involved in the project. Letters introducing the evaluation, its purpose, and procedures were sent to head doctors of partner institutions requesting permission to meet with the relevant staff. After that, interviews were arranged and conducted in person by the consultant between July and September 2010. Each person was told the purpose of the interview and that their participation was totally voluntary. Each gave verbal consent and most agreed to have the interview tape-recorded.

The interviews were conducted following a set of questions developed by the evaluation team. The interviewer wrote a set of summary notes for each interview, using the tape recording as needed to clarify issues and ensure inclusion of all key points.

The evaluation team also researched a number of relevant documents, including Ministry of Health of Ukraine orders related to cancer/breast cancer care or resources (including the National Programme on Oncology for 2007–2016), Ministry of Health National Standards on breast cancer services, and recently published articles about breast cancer care or outcomes in Ukraine. A working summary of the key findings was prepared.

National cancer registry data were studied for the years of 1996, 2000, 2005, and 2009, with an emphasis on the following indicators:

- Incidence (national, by oblast)
- Mortality (national, by oblast)
• Staging (national, by oblast)
• Data on surgery type (radical vs. breast-conserving) by oblast and by time period
• Rate of biopsy-confirmed diagnosis (national, by oblast)
• One-year survival rates (national, by oblast)

Data from six oblasts and Kyiv city were included: Odesa and Chernihiv Oblasts (sites of the original project) and control oblasts for comparison (Kherson and Kharkiv for Odesa, Cherkassy and Zhytomyr for Chernihiv). No oblast or city with relevant characteristics suitable for comparison to Kyiv exists in Ukraine.

Data analysis

For data analysis, a matrix of key topics was developed, and interview comments from each interview were listed in the matrix. Additional topics not originally included in the interview guide were added to accommodate comments given spontaneously by the interviewees. Comments were then summarized for each topic by the lead evaluator and reviewed for validity by the interviewer. Simple descriptive analysis of registry data addressed time trends and comparison between project and non-project oblasts.
Findings

It would appear from the interviews and other data collected that even ten years after the project ended, there is still a noticeable impact. With changing economic and political circumstances during the subsequent decade and in the absence of any reinforcement or follow-up support, we still find that some innovations were adopted and institutionalized even beyond the project areas, while others took root in the project areas and were at least maintained there. Naturally, there were also some project concepts and activities that declined or were abandoned after the project ended.

Tools and curricula developed by the project

Tools and curricula developed by the project, it was difficult to get a clear picture of how widely the various curricula are still being used, but all of them seem to be used at least to a limited extent. We were unable to get much information about whether they had been incorporated into official preservice or postgraduate curricula.

Mammography technician training

In Kyiv, they reported having adapted the original PATH mammography technician curriculum into one that they now use as their standard training program. In Chernihiv, the mammography technicians originally trained by the project continue to teach technicians from surrounding areas as more mammography equipment becomes available. For this training, they use the original PATH materials. In Odesa, they still have some of the technicians originally trained by PATH, but when they got a new machine through Avon Foundation, they received refresher training. They did not report that they provided any training to others.

Mammography training for radiologists

The mammography training module for radiologists based on the Breast Imaging Reporting and Data System (BI-RADS) that was translated by the Radiologist Association and printed by the project was widely distributed and is still in use. Dr. Babiy, who was head of the Radiologist Association at the time of the project, is now a professor at a postgraduate medical academy. He reported that the PATH module was used widely until a new special course in mammography was approved in 2010; that course still uses the BI-RADS classification principles.

Clinical breast exam training

The CBE curriculum developed and introduced by PATH was incorporated into the standard gynecology curriculum for nursing schools, as noted in a textbook from that time period. Nurse-practitioners and midwives also receive this training now. The role of PATH in developing the curriculum is even acknowledged in the textbook. The current evaluation was only able to document actual practice of CBE in Chernihiv, where it was confirmed that CBE really took hold; but informal telephone interviews confirmed that it is taught in several other oblasts and seems to be standard information. The Chernihiv Dispanser still uses the original PATH training modules to train about 150 to 160 general doctors and nurses in CBE each year.
Psychosocial support curriculum for nurses

We were unable to locate anyone at the nursing school in Kyiv familiar with the original PATH curriculum who could say whether components of it were included in the preservice training now, but a staff person there did confirm that the current curriculum does contain at least a few hours of instruction related to psychosocial support. In Chernihiv, they continue to provide in-service training to nurses (30 percent of whom already received training during the project) through an annual mini-conference, which consists of a two-hour lecture on psycho-emotional support. They note that they do not do an interactive approach because they lack a trained facilitator for this type of teaching.

Psychosocial support curriculum for survivor groups

Training for these groups seems to be a mixture of apprenticeship with a more experienced member, occasional lectures from guest speakers, and a few formal training programs. The PATH curriculum itself does not seem to be used any longer, although many of its principles have probably been passed down through the mentoring process. The curriculum requires a trained facilitator and it seems that the original facilitators did not encourage a new generation of trainers from within the group. Even without the formal training sessions, a more informal group education continues.

Continuing use of clinical/medical skills and activities

Clinical breast exam practice

As noted above, CBE clearly seems to have taken root in Chernihiv and elsewhere since it was eventually adopted into the official training curricula for nurses.

Mammographic screening protocols

The project introduced several concepts around mammography screening. One was the American BI-RADS classification system of mammography, which seems to have been widely disseminated. We were unable to ascertain with our limited data collection whether radiologists outside the project areas are actually using it in their daily practice. The single-view approach, which the project promoted as a cost-saving measure related to film supplies, was not ultimately adopted. Nor has the country developed an organized screening program, mainly due to lack of resources. The National Oncology Programme does not include screening programs or related budget allocations. According to a 2007 law, enterprises are responsible for organizing periodic examinations of certain categories of employees. In most places it remains an opportunistic program for those women who care to come in, although in Chernihiv there have been some outreach efforts in rural areas to educate and motivate women to come in. In both Odesa and Chernihiv, the Dispansers respond to requests from employers to screen their workers; in Odesa they note this is now limited because heavy industry is no longer functioning much there. In Chernihiv, certain government agencies and the oblast administration have arranged for mammography for their employees (covering the cost of film and other consumables), as have companies where trade unions are active. One leading radiologist who tried to establish an organized program with targets and guidelines in one raion or “district” of Kyiv reported that they ran out of funds and had difficulty getting film. He noted that there are no national indicators to monitor the extent of quality of screening.
Ultrasound-guided needle biopsy

One area that seems to have been solidly adopted was ultrasound-guided needle biopsy, at least in the project areas where training on the method was provided. All three project sites report that fine needle aspiration (FNA) biopsy is now usually done with ultrasound guidance, and core needle biopsy (practically unknown in Ukraine before the project) is also now done in some settings. It appears from at least one comment in Kyiv that biopsy guided by ultrasound is now done even beyond the project areas, but we were unable to confirm this. It may be truer of FNA, since one surgeon in Chernihiv commented that core needle biopsy is still not done in many big cities of Ukraine. In Odesa they report that they still have difficulty getting good-quality core needles, but they use the process for about 30 percent of their cases, depending on the stage of disease (FNA for stage 1 and core needle for higher stages). In Odesa, they estimated that they do 15 to 25 breast biopsies each month, all using ultrasound guidance. In Chernihiv, a surgeon acknowledged that they were initially skeptical about core needle biopsy but they now use it in 30 to 40 percent of cases. The doctors in Chernihiv who were taught during the project have subsequently trained several other doctors in the oblast to do it.

Breast-conserving surgery

A major focus of the project was breast-conserving surgery, since radical mastectomy was widely used previously and there was considerable skepticism about breast-conserving surgery. However, it appears that the project made a lasting change in this area, and breast-conserving surgery is now practiced extensively. In Odesa for example, the number of breast-conserving surgeries jumped from about 10 a year a decade ago to 150 to 170 a year now, constituting about 50 percent of the breast surgeries. Whereas they previously did mostly Halsted surgeries (removing the pectoral muscles), they now often preserve them. As one surgeon in Odesa reported, “These changes are directly related to the knowledge we received from PATH during study trips and also due to improved diagnostics.” He noted the importance of breast conservation for improving the quality of women’s lives, preserving their dignity, and saving their families.

Immunocytochemistry evaluation

The new diagnostic capacity, ICC, also seems to have taken root and spread more widely. While there was some sporadic use of it before the project, it has now become a routine procedure in all three project areas, and there was informal evidence that it was used in many other oblasts. Testing for tumor markers provides essential information to guide treatment selection. A leading pathologist in Kyiv maintains that stage-specific five-year survival has improved considerably as a result, to be closer to the rates in Europe. She maintains that the excellence in her lab now is directly related to what she learned during the project about structure and process organization and about appropriate equipment to use. She currently serves on a working group to incorporate correct quality control procedures into national norms and legislation. In Odesa, they managed to get the regional hospital to open a pathology lab with ICC capacity, and they routinely test for various biomarkers and use the information to guide their choice of chemotherapy. One surgeon noted that infiltrative/edematous tumors that were previously considered inoperable are now successfully treated because of knowing their hormonal status and being able to use appropriate chemotherapy. There are still some problems regarding the cost of the tests, which has apparently increased so that some patients cannot afford them.
Neoadjuvant chemotherapy

In Odesa, where a clinical trial was conducted, they continue with the protocol they tested during the project, and it has actually been included in the national standards of treatment by an order in September 2007 with only minor adjustments in dosage.

Cancer registry capacity

The same staff remain in place at the registry and continue to produce an annual bulletin, although the head of the registry has had some health problems and had to take medical leave (it was not clear how long it has been going on). However, they are no longer involved in many international collaborations. They noted that Chernihiv and Odesa are among their best oblast registries. While Chernihiv was already doing pretty well reporting when the project started, Odesa’s registry was considered weak and had problems with duplicate entries. It appears that the small technical support provided to the Odesa registry during the project led to sustainable improvements in performance.

Equipment and supplies

We did not expect to find much of the actual equipment still to be functioning ten years later, especially since some of the larger equipment was reconditioned used equipment already. The mammography machine donated in Kyiv worked reliably for ten years and was just replaced in 2008 with a new machine. The ultrasound machine and Kodak developing machine for X-ray film in Kyiv are apparently still in use and working well. One senior radiologist noted that experience with the mammography equipment donated by the project “changed the mentality of radiologists and oncologists” about the old Soviet equipment, helping them see how deficient it was. He noted that newer equipment is gradually appearing in more places. In Odesa, the mammography machine provided by PATH “worked ten years non-stop” and has now been passed on to one of the raion hospitals where it still works. It was also reported that there are many more mammography machines there now than before. The mammography machine in Chernihiv worked until 2009, but has since been passed onto another small hospital; the film developer is still working. Another mammography machine received from a separate source in 1998 is still running, in part because PATH paid for its maintenance and repair during the project. The project had tried to set up reliable film supply sources, but several respondents reported that film supply is still sometimes a problem.

Psychosocial support during and after treatment

Provider-patient communication practices

In all three project sites, respondents noted that attitudes and behavior of doctors and nurses had changed since the project. In Kyiv, one doctor reported that doctors had become more open, talking more frankly with patients; however, that same person said that doctors (and nurses for that matter) often do not have much time to talk with patients. In Chernihiv, the head nurse in the hospital said that nurses are now trained to provide emotional support to women, to not be afraid of patients’ questions, and to console patients. However, even she stated that “it is not part of their official job description.” A doctor in Chernihiv reported that the doctors who had been trained by the project used their counseling skills now, but remarked that there was inadequate
attention to communication issues in doctors’ education and that the issue is never raised at professional conferences. In Odesa, they reported they now had a full-time psychologist working in the hospital.

When asked specifically about the practice of telling women their cancer diagnosis (taboo when the project started), respondents in Chernihiv said it was the usual practice now (perhaps 80 percent of the time) but that some women were still not ready to hear it and the decision to tell the diagnosis had to be made according to the individual. In Odesa, however, one oncologist said that 75 percent of women cannot be told their diagnosis directly, for fear they will become suicidal. This doctor also said the matter was governed by national legislation and would have to be changed at a higher level.

**Peer support**

Survivor groups are functioning not only in the project area but in numerous other cities throughout the country. Members of these groups visit women in the cancer hospitals and also provide support for each other after treatment. There are two clusters of groups: those that were started by the PATH project (or spin-offs from those) and those started by Dr. Maistruk, who was a consultant to the PATH project and worked with survivor groups afterwards. Many of the groups have officially registered as organizations and have joined a national federation of groups, perhaps in part because of another USAID-funded project that supported NGO development from 2003 to 2006. Nearly all seem to struggle to find sufficient resources to maintain their activities. They seem to fluctuate in activity level, often related to the health or demise of key members. In Odesa and Chernihiv, they report making visits to individual patients as well as organizing group meetings. Groups in all three sites reported holding meetings with guest speakers and doing outreach to raise public awareness. The Kyiv group has registered nationally, organized summer training programs, attended conferences, organized marches, and reached out to groups in other cities. Several groups reported that they organized recreational outings for their members. While Odesa and Chernihiv groups have been welcomed in the hospital, the National Cancer Institute director was not very receptive, so Kyiv groups were not allowed to come despite staff requests for them. The Chernihiv group has traveled throughout the oblast contacting former patients and organizing mini-conferences for them. There are now small groups functioning in many raions of the oblast. The rehabilitation room set up in the Chernihiv hospital with project support still functions, with a massage table, exercise bars, and literature.

**Policies and practices have been adopted by other regions (non-project sites)**

Given the limited opportunities to collect data from other regions, beyond the original project sites, it was difficult to determine directly the extent to which policies and practices promoted during the project had spread elsewhere. Table 1 summarizes the evidence from anecdotal reports given by people in the project areas as to which interventions were institutionalized through policy or guidelines, which were spread beyond the project area, which were maintained in the project areas, and which proved unsustainable in current circumstances.
Table 1. Summary of Impacts

<table>
<thead>
<tr>
<th>Intervention area</th>
<th>Changes that spread beyond project areas</th>
<th>Changes that prevail in project areas</th>
<th>Interventions that were not maintained</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening (mammography and CBE)</td>
<td>• Concept of prophylactic examinations included in national standards of 2007&lt;sup&gt;a&lt;/sup&gt;</td>
<td>• Screening mammography in Chernihiv</td>
<td>• Single-view mammography</td>
</tr>
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<td></td>
<td>• CBE for primary screening</td>
<td>• Equipment: mammography, film processing, ultrasound</td>
<td>• Understanding of “screening” definition (i.e., asymptomatic)</td>
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<tr>
<td></td>
<td>• CBE curriculum</td>
<td>• Mammography database in Chernihiv</td>
<td>• Organized screening program</td>
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<td></td>
<td>• Ultrasound-guided biopsy</td>
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<td></td>
<td>• Mammography training for radiologists and technicians</td>
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<tr>
<td>Screening</td>
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<tr>
<td>Diagnosis</td>
<td>• ICC</td>
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<td></td>
<td>• Methods for diagnosis</td>
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<tr>
<td>Treatment</td>
<td>• Breast-conserving surgery</td>
<td>• Neoadjuvant chemotherapy in Odesa</td>
<td></td>
</tr>
<tr>
<td>Psychosocial support</td>
<td>• Survivor groups for peer support</td>
<td>• Psychosocial support for in-patients; telling of diagnosis</td>
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Abbreviations: CBE, clinical breast exam; ICC, immunocytochemistry
<sup>a</sup> Limited data on extent of use

Patient outcomes

Patient outcomes were determined both by anecdotal reports and by looking at trend data from cancer registry reports. However, the registry data from the earlier periods at the start of the project are not available electronically, and registry staff were unable to provide data for the selected comparison oblasts on some variables. Also, the comparison oblasts (selected for general similarities to the project oblasts) turned out to have dissimilar baseline data on certain outcome indicators, which complicated the planned comparisons. We did not have the resources to explore possible reasons for some of the differences identified in baseline or post-project evaluation data.

According to those who were interviewed in the project sites, they are seeing more diagnoses of breast cancer at earlier stages (1 and 2) than before. In Chernihiv, for example, the hospital director reported that late-stage at diagnosis had declined from 41.3 percent in 1995 to 27.8 percent in 2009. This is borne out by the registry data for Chernihiv and Odesa, which saw increases in stage 1 and 2 diagnoses from 2001 to 2009, from 60 to 72 percent in Chernihiv and from 70 to 80 percent in Odesa.

Of the two comparison districts for Chernihiv, Cherkassy started at a similar level and had a parallel rise, while Zhytomyr started much higher (76 percent) and actually saw a small drop...
over the eight-year period. Odesa’s comparison oblasts also displayed a mixed picture, with Kharkiv having a slightly larger gain than Odesa and Kherson starting a little higher and having a smaller gain. Kyiv, which started with the highest proportion, actually saw a decline—from 89 to 81 percent—in the percentage of early-stage diagnoses (see Figure 1).

**Figure 1. Early Diagnosis, 2001–2009**

Better patient survival is measured as one-year and five-year survival after diagnosis and depends both on stage at diagnosis and treatment success. In the interviews, both Chernihiv and Odesa experts claimed that their five-year survival rates were about 60 percent compared to the national average of about 52 percent. In the registry data, they report one-year survival data since it is considered more reliable than five-year survival data. Using 1996 and 2009 data, it appears that most of the oblasts started out at similar one-year survival rates between 83 and 86 percent (except Kyiv, which was 92 percent) and all but Kherson and Kyiv showed some improvement (between 2 and 3 percent) in one-year survival. In an interview, it was claimed that Chernihiv one-year survival had climbed from 84.4 to 92.2 percent, but this was not confirmed by available registry data. In the registry data, Cherkassy and Zhytomyr showed slightly better improvement than Chernihiv, while Odesa had slightly better performance than Kharkiv and much better than Kherson. Judging from the fluctuations in rates in 2001 and 2005 and the narrow range of results, these differences are unlikely to be significant (data not shown).

Registry data confirm an increase in the proportion reportedly identified by screening, although this trend is evident in all the oblasts except Kherson (see Figure 2). It is unclear how well these data actually represent cases identified by screening, since the definition understood by many doctors is “women who come on their own, as opposed to being referred by another health worker.” In all likelihood, the reported figures include women truly asymptomatic and identified by screening and women who came in because they had symptoms or concerns. Chernihiv, which started at a very low level of 18 percent in 1996, more than doubled the figure by 2009 (37 percent). This is almost surely due at least in part to the increased number of screening mammograms and CBEs that were done. Its comparison oblasts, which started at higher levels, had similar gains and remained higher. Odesa, which started at a higher level (37 percent) also had a solid gain (to 50 percent), but was far surpassed by Kharkiv, which reported a spectacular
rise from 19 to 53 percent during this time period. Neighboring Kherson started at a level similar to Odesa but declined to 25 percent by 2009, while Kyiv started higher and had a steady improvement over the 13-year period.

**Figure 2.** Cases identified by screening, 1996–2009

The expected benefit from screening is most easily seen in the proportion of cases identified in stage 1, when treatment is least burdensome and most successful. Despite the uncertainty noted above as to how “detection during screening” is interpreted in Ukraine, there does seem to be some down-staging evident in the project areas, compared with the selected “comparison” oblasts (see Figure 3). While pre-project data were not available, data from 2005 and 2009 show that project areas (Chernihiv, Odesa, and Kyiv) had higher proportions of their “screening detected” cases identified in stage 1 (suggesting true and effective screening). It is interesting to note that comparison oblasts Zhytomyr and Kherson had dramatic rises during this time period, although we have no direct data on the causes of these increases. Although Kharkiv and Cherkassy reported an increase in screening during this time period (see Figure 2), this screening was less successful in identifying women in early stages (Figure 3).

**Figure 3.** Percent of stage 1 cases among women diagnosed during screening, 2005
Trends in breast-conserving surgery, which is also related to stage of diagnosis, are difficult to detect in the registry data because: 1) surgeries are reported in categories of tumor removal (lumpectomy), quadrantectomy, sectoral resection, and mastectomy; 2) several oblasts (including Odesa and Kharkiv) don’t specify surgery type in their reports; and 3) earlier data were not available for this review. Data from 2005 through 2009, though, clearly show that Chernihiv (which has more screening and more stage 1 detection) has the highest proportion of lumpectomies in the country (23 percent of all breast surgeries); no other oblast has more than 9 percent and most have fewer than 5 percent. Considering all surgeries except mastectomy as being breast-conserving, Chernihiv and Kyiv are still far ahead at 36 percent and 42 percent respectively. The comparison oblasts that have data available report 26 to 28 percent of women as receiving breast-conserving surgery.

Improved diagnosis, particularly with information on biomarkers through ICC, was noted by several pathologists and surgeons interviewed as a major and lasting outcome of the project, and registry data lend some weight to this claim. Registry data only report the proportion of cases with a morphologic diagnosis (i.e., based on biopsy rather than just clinical impression) rather than specifying determination of biomarkers. While Chernihiv, Cherkassy, and Kherson already had relatively high levels of biopsy-confirmed diagnoses (greater than 90 percent) in 1996 and remained at those levels in 2009 (data not shown), Odesa and Kyiv both had substantial improvements. Odesa went from 85 percent in 1996 to 95 percent in 2009, while Kyiv climbed from 90 to 97 percent. Zhytomyr saw a remarkable improvement, from 85 to 99 percent, while Kharkiv started at 74 percent in 1996 and only improved to 79 percent by 2009.

Mortality data from the cancer registry show a mixed picture. Chernihiv and Odesa experienced slight rises over the 1996 through 2008 period (from 23.2 to 26.7 and from 34.8 to 36.2, respectively), while Kyiv had a slight drop in the middle of the period but returned to its pre-project rate by 2009. Three of the comparison oblasts had increases in mortality of 4.6, 3.3, and 6.1 deaths per 100,000 women, while Zhytomyr stayed at a relatively steady mortality rate throughout the 13-year period.

**Estimated beneficiary numbers**

It is difficult to estimate the number of women who may have benefitted from the improvements in care stimulated by project activities, but we focused on those areas where the activities clearly had a positive impact. Table 2 summarizes the estimates and the assumptions on which they are based. The provision of mammography equipment (much of which functioned at least 10 years after it was delivered) and the improvement of both radiologist and technician skills affected the care of thousands of women. This was especially true for screening mammography, but also for diagnostic mammography. It was impossible to estimate the effect in other oblasts that benefitted from the training provided by Kyiv to about 150 radiologists and at least 10 technicians from other hospitals.

It is impossible to estimate the number of patients whose care improved as a result of their doctors having participated in various seminars and national meetings sponsored by the project where modern information was presented and discussed. We know that doctors from many oblasts attended the final summary conference, and at least some of them were likely to have adopted some of the practices discussed there.
Survivor groups had an ongoing impact both on their active members and those women who derived support from outreach visits while in the hospital or from occasional educational or recreational events organized by the groups. Additional groups were organized in other oblasts beyond the project areas based on the model and often supported by individuals from the original project. There was no way to estimate the number of women who benefitted from the public education efforts undertaken by these groups to encourage women to seek screening or to change their public attitudes toward breast cancer survivors. With regard to doctor and nurse interactions with patients and provision of psychosocial support, the evidence is mixed. It seems that the clearest effect was in Chernihiv, with lesser impacts in Odessa and Kyiv. However, there is no way to know how many nurses were trained with the new curriculum developed by the project or were exposed to the changed attitudes and interaction styles of those who were trained as a result of the project. Even with these very conservative estimates, it is clear that tens of thousands of women have been helped over the years since the project ended.

**Table 2.** Estimated beneficiaries for selected interventions, 2000 through 2009

<table>
<thead>
<tr>
<th>Interventions</th>
<th>Number of women benefitting</th>
<th>Assumptions, comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Chernihiv</td>
<td>Odessa</td>
</tr>
<tr>
<td>Screening mammography</td>
<td>40,900</td>
<td>40,000</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnostic mammography</td>
<td>3,400</td>
<td>10,000</td>
</tr>
<tr>
<td>Survivor groups</td>
<td>820</td>
<td>2,400</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosocial support to patients</td>
<td>2,960</td>
<td>2,900</td>
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</tbody>
</table>

**Various other observations on project effects**

A few general comments about the project emerged during the interviews. Efforts to introduce a more multidisciplinary approach to treatment planning and patient care seemed to have only a limited effect. Most people interviewed said the surgeon still makes most of the treatment plans according to standard guidelines, but the radiologist and medical oncologist do get to review and comment on them. Actual case review sessions that bring all specialties together are called only for complicated cases. A leading doctor in Kyiv noted that the project’s success in organizing and networking doctors in Ukraine to work together in solving the issues of breast cancer changed the “consciousness of our doctors, to prove to them that changes are needed.” A doctor in Chernihiv said, “Things which we have now in the Dispanser were developed as a result of
this project; but when I talk to other regions in Ukraine they did not benefit from such assistance.”

With regard to public attitudes, a doctor in Chernihiv commented that “ten years ago, women in general and our patients were far from understanding the reality of their disease and what to do about it, but now everything has changed. First of all, a lot has been done during all these years to inform the general population about cancer, how to protect yourself against it, what to do if you have it, etc. The word ‘cancer’ began to be spoken, whereas before people were even afraid to say it out loud. Women are not afraid of the word; instead they start asking what to do, very constructively. In Chernihiv, the work of the PATH project has contributed significantly to it and changed the perception. Many contacts we have now with mass media, newspapers, and different organizations, and the level of awareness among women has increased.”
Discussion

Project success was defined as creating lasting positive changes that were adopted nationally or spread to non-project areas, or were at least maintained in the project areas. Many of the tools such as training curricula, some of the clinical practices (e.g., ultrasound-guided biopsy and breast-conserving surgery), and the development of survivor groups for peer support spread well beyond the project areas. It seems that fatalistic and stigmatizing public attitudes about cancer have changed substantially over the years, and several interviewees pointed to the PATH project as the starting point for that change. Other interventions (such as organized screening mammography, neoadjuvant chemotherapy, and psychosocial support for patients) were maintained locally, but not adopted widely elsewhere. Perhaps these latter practices were more dependent on individual skills, interest, and commitment. Practices designed to conserve resources—but not widely practiced in Europe or North America—were not adopted long-term, such as single-view mammography. Ones that went counter to strongly entrenched behaviors, such as a team approach that called for regular consultation of all medical disciplines, did not get institutionalized in the short life of the project. It seems that Ukraine was not quite ready to accept some of these new approaches, and more sustained advocacy would have been needed to install the changes in attitude. Many approaches would have required a complete transformation in old habits and beliefs. While some doctors became more open about disclosing a cancer diagnosis to patients, for example, others continued to be constrained by widely accepted myths about the attitude of the people with cancer toward knowing their diagnosis.

It is remarkable that in less than four years, so many improvements were made and incorporated into general practice. It seems this was at least partly due to the diversity and high caliber of the technical experts who served as consultants to the project. The personal dedication demonstrated both by the consultants and the project staff (many of whom had strong personal commitments toward Ukraine and breast cancer care) reportedly inspired respect among Ukrainian colleagues and enhanced their willingness to cooperate. Detailed discussions with Ukrainian colleagues and incorporation of their input wherever appropriate contributed to the positive collaboration. Several of the collaborations continued after the project, and some continue to this day.

With regard to the various curricula, it was not an original objective of the project to get them embedded in the preservice or postgraduate curricula. There were some attempts to initiate this process toward the end of the project, but this is a time-consuming process and there were no champions to take it on and complete the effort after the project ended. Apparently, PATH’s training approach (which was more interactive and hands-on) was different from the standard didactic methods in general use in Ukraine, which may have reduced the likelihood that the curricula would be adopted without active and sustained advocacy and training of trainers. Given these constraints, it is perhaps notable that so many elements of the various curricula continue to be used and incorporated into wider use.

The inconsistent pattern of patient outcomes related to down-staging of disease, that is, the proportion of women diagnosed at early rather than late stages, is difficult to explain without examining what was going on in other oblasts. It is hard to discern the extent to which the project contributed to increases in stage 1 to stage 2 detection; increases in the comparison oblasts could
be a result of ongoing upgrading of the health system in general, better understanding among the
general public and women specifically of the importance of paying attention to breast health, or
better access to mammography nationally. Since we know that systematic screening programs
were not instituted even in the project oblasts, it is understandable that they might not show any
particular advantage over other oblasts.

The one-year survival data are also difficult to interpret without knowing what was going on in
the comparison oblasts. Improved survival is generally attributable to earlier stage diagnosis
and/or better treatment. Odesa, where the neoadjuvant chemotherapy protocols were instituted,
showed a more dramatic improvement in survival than its comparison oblasts. Chernihiv did not
make significant changes in its therapeutic approaches, and apparently did not have substantially
more early-stage cases than its comparison oblasts, so it is perhaps understandable that its
performance would be similar to its neighbors.

While these results provide valuable and rare insights into the lasting effect of a project ten years
after its end, the data are clearly limited in several ways. The biggest limitation was the limited
geographic scope of the interviews, confined to the oblasts where the project was carried out,
which prevented us from assessing possible impact beyond these areas—despite the fact that
there were limited activities in other parts of the country, a national workshop sharing findings at
the end of the project, and the natural diffusion of ideas and transfer of skills through training
programs. In addition, there may have been some tendency by interviewees to focus on positive
results to please the interviewer, although we used an interviewer who was independent from
PATH. Since specific examples were also elicited, and some negative comments were offered as
well, this does not appear to be a major source of bias. The long time lag meant that memories
were sometimes hazy, so some impacts related to the project may not have been captured.
Choice of the comparison oblasts for the registry data was done without access to extensive
baseline data and there was no opportunity for interviews in the comparison oblasts, so it is
difficult to interpret factors at work in similar or different outcomes. In addition, the registry data
may have been incomplete or inaccurate, and it seems there were differences in how some items
like surgery type were coded. Unfortunately, we did not have the opportunity to interview
patients about psychosocial support they may have received in the hospital or through survivor
groups.

**Areas for potential future work**

While many areas needing support or strengthening were identified during the course of the
evaluation, there were three that seem both important and relevant to PATH competencies and
interests:

1. More work is needed to identify appropriate mechanisms for peer support, including
means for basic financing, membership recruitment and retention strategies, and training
for counseling and management.

2. Although scientific communication is much more open now than it was ten years ago,
there is still a need to update screening, diagnostic, and treatment protocols in light of the
many advances of the past decade. PATH could play a valuable role by facilitating that
process through workshops, expert consultations, and literature summaries.
3. It is clear that more work is needed to establish the concept and optimal methods for an organized mammography screening program in Ukraine. There has been an influx of modern mammographic machines in the country, but apparently without any guidance or leadership for integrating them into an efficient and effective screening program. Even with additional mammography capacity, there is not enough to screen all women who need it, so continued strengthening of CBE capacity and practice is needed. Working to expand the reach of the interventions already put in place, building on the network of trained specialists still practicing in Ukraine would be a logical follow-on investment.
Conclusion

The Ukraine Breast Cancer Assistance Project, funded by USAID for just under four years, has had a lasting impact in several critical areas of breast cancer care. An evaluation undertaken with a small internal PATH grant in 2010, ten years after the end of the project, showed that many components of the project are still in place and some have actually spread well beyond the project sites. Improvements in clinical practice through training such as clinical breast exam and mammographic imaging and changes in treatment such as ultrasound-guided biopsy and breast-conserving surgery greatly improved the quality of care received by women in Ukraine. Equipment that was provided functioned well beyond the life of the project, and many of the educational tools that were developed were incorporated in one form or another into the development of health worker skills. Not all interventions were maintained, however; in particular, those that required changes in deep-seated attitudes were least likely to have been sustained. Due to the limited nature of the evaluation and the weak cancer data system, it was not possible to demonstrate a clear relationship between the project and current patient outcomes, but there are some encouraging trends that suggest screening increased in project areas and resulted in earlier diagnosis of disease (which usually means better survival). The breadth of areas affected by the project, despite the relatively small budget, was most likely due to the high quality and continuous involvement of the technical specialists assembled as consultants for the life of the project and a project team with a deep understanding of the Ukrainian context and dedication to improving breast cancer care for Ukrainian women.

Acknowledgments

The project team would like to thank PATH leadership for making the funds available for this evaluation and Julia Zhitkova for conducting the interviews and compiling the data.
Annex 1. People Interviewed for Evaluation

Kiev

National Cancer Institute (former Ukrainian Research Institute of Oncology and Radiology)
1. Schepotin, Igor Borisovych: Director ; Ministry of Health Chief Oncologist
2. Khrokhmaleva, Luidmila Pavlovna: Head of Radiation Diagnostics; Mammographer
3. Shevchenko, Svetlana Vasilyevna: Mammography Technician
4. Sumkina, Elena Vladimirovna: Scientist in the Department of Cancer Epidemiology and Cancer Registry
5. Gulak, Luidmila Olegovna: Scientist in the Department of Cancer Epidemiology and Cancer Registry

Kiev City Oncology Hospital
1. Zakhartseva, Luibov Mikhailovna: Head of Pathology Department
2. Babiy, Yakov Stepanovich: Professor and Chair of Radiation of the Shupik Post-Graduate Education Medical Academy; former Chief Radiologist of the Ministry of Health; President of the Ukraine Association of Radiologists
3. Lopata, Larisa Nikolaevna: President of “Amazonki,” a Kiev city nongovernmental organization; Head of “Razom proty raku” (Together against cancer), an all-Ukrainian nongovernmental organization of people with oncological disabilities

Odesa

Odesa Regional Oncology Centre (Dispanser)
1. Bondar, Serghey Vladimirovich: Head of Mammology Centre; Chief Oncologist of Odessa Region
2. Suprun, Andrey Evgenievich: Head of Outpatient Department of Mammology Centre
3. Martsinkovskaya Natalia Vadimovna: Head of Chemotherapy Department
4. Fesenko, Natalia Lvovna: Director of “Victoria,” a nongovernmental organization

Chernigiv

Chernigiv Regional Oncology Centre (Dispanser)
1. Zotov, Vladimir Nikolaevich: Head Doctor and Chief Oncologist of Chernigiv Region
2. Shatalyuk, Alla Stepanovna: Doctor at Outpatient Department; Head of nongovernmental organization “Victoria”
3. Zaika, Alexander Nikolaevich: Surgeon-oncologist at Inpatient Department
4. Zakharchenko, Natalia Mikhailovna: Head of Radiation Diagnostics Department
5. Stolinets, Lidia Nikolaevna: Head Nurse
6. Fialkovsky, Alexander Adolyevich: Psychologist