Special Report

Early Detection of Breast Cancer Using a Self-Referral Mammography Process: The Kaiser Permanente Northwest 20-Year History

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Abstract

Objectives: Breast cancer is the most common malignancy in women in the Kaiser Permanente Northwest Region. Ninety-five percent of women later found to have breast cancer were seen an average of 5 times in the medical offices in the year preceding diagnosis. Until 1991, screening mammography depended on clinician ordering. However, 20% of at-risk women were left out of the process because they had no clinician visit in the preceding year. Self-referral mammography was introduced as one of a number of processes to provide more comprehensive screening.

Methods: The Region's tumor registry database was examined to assess the effect of self-referral screening on early diagnosis, stage of disease, and family history.

Results: From 1991 to 2010, more than 995,000 mammograms were performed and 8752 breast cancers were diagnosed. By 2011, almost 50% of all mammograms were scheduled using the self-referral process, with more than 25% of cancers diagnosed through this process that year. The tumor registry provided both active and passive roles in the quality of cancer screening.

Discussion: The expected result of improving access to screening has been demonstrated over the last two decades. Beginning with the self-referral mammography program, each successive effort enhanced overall organizational effectiveness of care for the average-risk patient but failed to translate into any improvements for the higher-risk patients. As the number of screening tests done is used as the sole measure of screening effectiveness, segments of the at-risk population are likely to be missed, compromising overall early detection efforts.

Introduction

Primary care clinicians are called on to assess and integrate large amounts of information, and with the complexity of ongoing care needs, preventive screening is often a secondary consideration during the office visit. Over the 20-year study period, 95% of patients with a diagnosis of breast cancer, colon cancer, and melanoma were in the medical offices 4 to 5 times in the preceding year. Until 1991, mammography screening in the Kaiser Permanente (KP) Northwest (KPNW) Region was limited to clinician ordering. It was also observed that 20% of women had not been seen by a primary care clinician during the year and could thus not have breast cancer screening initiated. To improve access to screening services to the average-risk population, a self-referral mammography process was introduced. After an initial trial period, the program expanded to 31 medical and dental offices in the Region.

The request process for self-referral mammography was designed to be easy and accessible and to provide both guideline-based mammography and clinical breast examinations. Although this process shifted initiation of screening from the clinician to the patient, it was critical that it be seen as supporting the clinician-patient relationship. With continuous system improvement and integration over time, the overall percentage of women screened increased, while the stage at diagnosis decreased.

History

Since 1945, KPNW, a prepaid health care delivery system operating in Oregon and southwest Washington, has emphasized preventive care. By 2011, the medical program was serving more than 470,000 members. In the 1970s, breast imaging in KPNW was limited to patients with breast complaints. Mammography was ordered only after a clinician's breast examination. In 1983, mammography began to be used to screen asymptomatic women. With the certification of a regional tumor registry in 1960, cancer care was documenting and tracking outcomes. In 1976, the role of the registry initiated a "red dot" clinician reminder system to ensure that highly suspicious x-ray findings were evaluated completely in the subsequent 6 weeks. As more mammograms were obtained, interpretation became more difficult as the size of cancers that were detectable was smaller and more questionably suspicious areas were seen that needed follow-up. The need to repeat imaging at 3 or 6 months became the responsibility of the overworked clinician, leading to the creation of the "yellow dot" system in the tumor registry, modeled after the "red dot" system. During the last 30 years, 35% of "red dot" cases have proved to be malignant, whereas less than 2% of the "yellow dot" cases were. These tracking databases provided performance measures for radiologists who were interpreting thousands of mammograms yearly.

This review spans 3 phases: 1983 to 1990, 1991 to 2001, and 2002 to 2010.

1983 to 1990

Before 1983, because mammography was limited to women with breast complaints, almost no screening mammography was performed. By 1983, national studies began demonstrating the benefits of screening for the early diagnosis of breast cancer. It became the responsibility of the individual clinician, or

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the insistent patient, for mammography to be ordered. Within months, mammography began to be performed more frequently in women between the ages of 50 and 70 years.

By 2011, the percentage of breast cancers diagnosed through the self-referral mammography pathway had increased to more than 25%.

In 1989, a multidisciplinary Breast Cancer Task Force examined the overall program, focusing on the Region's alignment with national guidelines. The deliberations with the Departments of Primary Care, Surgery, Radiology, Oncology, and Pathology and with KP Center for Health Research researchers provided the Region with a comprehensive roadmap. The task force recommended screening mammography every 1 to 2 years for women between 40 and 75 years of age, after clinical breast examination. They also recommended improvements in mammography capacity, clinical examination availability, and patient and staff education. Radiology efficiency improvements included report standardization, the introduction of a motorized mammography viewer (Rolloscope, Control Research, Inc; Redondo Beach, CA), and increased support staffing. As the volume increased, the radiologists adopted a blinded double-reading process. Managerial sponsorship was critical in accomplishing the goals.

1991 to 2001

By early 1991, mammography screening had increased, but the requirement for a clinician to initiate the process meant that many at-risk women were not getting a mammogram. For that reason, a proposal for self-referral mammography was put forward to provide an opportunity for patient-directed access to both imaging and breast examinations. Because the patients we were missing were already coming to our facilities, a low-cost outreach campaign to these women through our clinics was a practical first step.

On September 30, 1991, the self-referral mammography program was piloted at one medical office, and after a 2-month trial, the project was rapidly expanded to all check-in modules in each of the 31 medical and dental clinics. Using medical office resources to identify women wishing to be screened as well as a centralized triage to establish appointments, the system was enthusiastically adopted. From the outset, women were provided a consistent message about the value of screening, age guidelines, and the importance of clinical breast examinations. Clinical breast examinations were scheduled for those women who had not had a current examination in the past 6 months, or who did not expect to get a follow-up appointment with their personal clinician in the following 6 months.

Three challenges faced the design team for the self-referral mammography program. These included triage and scheduling, results reporting, and meeting the follow-up needs of the patient who did not have a primary care physician. Triage and scheduling of mammography and clinical breast examinations could be managed from information provided in the patient request form. The request form asked:

- Have you had a mammogram in the last 12 months?
- Who is your primary physician?
- Have you had a breast physical examination in the last 6 months, or do you expect to have an appointment with your physician in the next 6 months?
- Have you had either a breast implant or personal history of breast cancer?
- Do you have either a new breast lump or bloody nipple discharge?

For women who had a breast complaint (pain, mass, or discharge) or were outside the age range in the mammography guideline, a Breast Clinic appointment was arranged. Those patients meeting the guidelines for screening had a mammogram scheduled and clinical breast examinations, if required. For patients who were not yet due for screening, a future appointment was offered. In the first year, screening mammography (2-view imaging) was scheduled for 93% of women, with 7% subsequently triaged for diagnostic mammography (2-view mammogram with additional compression and magnification images and ultrasound imaging).

Several issues in the reporting of results were also addressed by standardizing the radiology report adjusting the following text:

- Normal mammography result, with a recommendation for mammography in 2 years.
- Normal mammography result, with a recommendation for mammography in 1 to 2 years.
- There is a need for further imaging studies. A radiologist-supervised diagnostic mammogram will be scheduled. This evaluation might include additional mammography views and possibly ultrasound imaging.

Suspicious ("red and yellow dot") studies were dictated individually, and results were directed to the patient's clinician and the registry reminder program. The process was improved by linking report transcription to an automated printing and mailing system, so that a patient letter was mailed within 24 hours and a copy directed to the ordering clinician, thus eliminating the need for the clinician to perform these steps directly.

Because some women who went through the screening process were not associated with a primary care physician, it was necessary to establish a clinician for follow-up care for these members. An individual who could be responsible for them was identified to ensure that results were seen and clinical follow-up occurred.

Table 1. Breast cancer screening at Kaiser Permanente Northwest

Initiative	Year begun
In-office	
Routine physical examinations at Health Appraisal Centers	1970-1995
Self-referral mammography program	1991
HEDIS initiatives	2003
Panel Support Tool	2006
EMR Best Practice Alerts	2007
Outreach	
Self-referral mammography program expanded to KP Dental	1992
EMR	1994
Safety Net program	1995
HEDIS initiatives	2003
Interactive phone calls, letters, birthday cards	2008

EMR = electronic medical record; HEDIS = Healthcare Effectiveness Data and Information Set; KP = Kaiser Permanente.

In 1992, the Safety Net program was proposed to reach out to women in the age range 52 to 69 years who were not receiving screening tests at recommended intervals.[1] Rather than depend on the passive in-office marketing of the self-referral mammography program, an active outreach (out-of-office) program was designed using the computerized databases in radiology, Membership Services, and the laboratory. With scripted breast and cervical cancer screening messages, the Safety Net was launched in 1995. The Safety Net outreach in 1997 and 2000 identified 14% and 16% of all the breast cancers, respectively.

In 1994, KPNW leadership convened a second Breast Cancer Task Force to review our program's progress. The Breast Cancer Task Force, using decision-analysis tools, redefined the age and frequency screening guideline and introduced a shared-decision-making process for women younger than age 50 and older than age 75 years. Also in that year, a regionwide outpatient electronic medical record (EMR) was introduced. Although the Region still depended on paper charts for inpatient care, the insurance, radiology, laboratory, and scheduling databases that were operational could be used to identify and manage the at-risk populations. When the EMR was implemented, the automated ordering and charting platform permitted an expansion of preventive care activities, and other automated databases functioned to alert clinicians when guidelines were not being met. Although many prevention activities could be automated, staff was often reluctant to relinquish that responsibility.

2002 to 2010

By 2002, prevention and early detection programs in the Region had been greatly advanced by the quality systems that had been developed. As noted in the Institute of Medicine's *Crossing the Quality Chasm* vision for the 21st century,[2] our systems were in place, but having a functioning infrastructure is different from demonstrating effective performance. In 2002, KP participated in the development of Healthcare Effectiveness Data and Information Set (HEDIS) metrics, and the KPNW Region was stimulated to focus on opportunities to demonstrate performance. With the HEDIS measures, purchasers, clinicians, and patients were able to consider a health insurer's performance against evidence-based targets in addition to costs of care. Although guidelines were in place and performance metrics were clear, the processes established to carry out the guidelines needed to be examined to identify gaps and to streamline the system. Examination of our screening processes revealed that "all clinical contacts were an opportunity for improving care." We knew the patients requiring screening were coming to our offices, but we needed to take the next step.

In 2006, the EMR was programmed to provide the primary clinician and office staff a patient-specific prevention profile, highlighting current care gaps. The Panel Support Tool compared a patient's current health maintenance status with the screening guidelines. What previously required clinician time and effort was now provided easily by the computer system, and the profile was always available when the chart was opened. In May 2007, the Best Practice Alert system was added, including a provision for identifying the need for mammographic screening and providing test ordering with minimal effort. This system was supplemented by active outreach programs (Safety Net, letters, phone calls, follow-up reminder system), as shown in Table 1. Throughout these phases, organizational support was critical to the program's success.

Methods

The KPNW Region provides medical care to more than 470,000 members in southwest Washington and in Oregon, the Portland metropolitan area and south to Salem. Features of the program that were helpful in developing self-referral mammography included a historic prevention mission, a unique individual health record number, a unified medical record, organizational databases for membership, laboratory and radiology services, an accredited tumor registry with additional high-risk tracking capability, and a strong collaboration between the medical and Health Plan leadership.

From the KPNW tumor registry, the database provided age, stage, and treatment information on the 8752 new cancers diagnosed during the study period. In 1989, the tumor registry added an additional data field to all new cases abstracted that defined the case as symptomatic or screen-detected. A symptomatic malignancy was defined as one diagnosed after a clinical examination finding or breast complaint. Cases lacking these features were considered screen-detected. The tumor registry included documentation about the self-referral mammography ordering process. These designations have been used to assess the evolution of screening effectiveness, including the influence of the in-office and outreach activities.

Results

Impact of Self-Referral Mammography

From 1991 to 2011, a total of 8752 new breast cancers were diagnosed. There were 658 patients who received a diagnosis through the self-referral mammography program since 1991. The

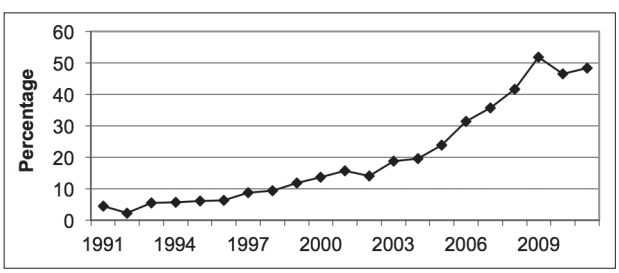

Figure 1. Percentage impact of self-referral mammography on mammography: 1991-2011.

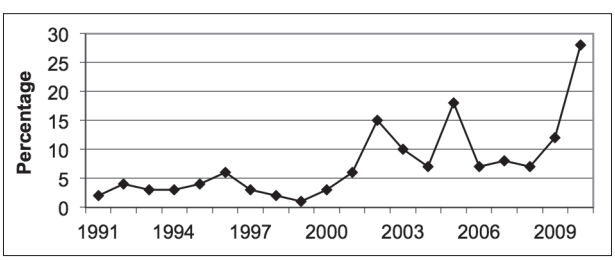

Figure 2. Percentage of breast cancers diagnosed through self-referral mammography: 1992-2011.

number of mammography examinations ranged between 40,000 and 60,000 examinations annually.

The impact of the self-referral mammography program was small in the first decade (Figure 1), but by 2001, 1 of 7 women (15.7%) used the self-referral program for scheduling. Many patients who initially used self-referral mammography continued to choose self-referral mammography, making it their preferred option. Between 2009 and 2011, 50% of mammograms were scheduled using this pathway. By 2011, the percentage of breast cancers diagnosed through the self-referral mammography pathway had increased to more than 25% (Figure 2).

Incidence and Prevalence

The incidence rate of cancers in a regularly screened population is 1 to 3 per 1000 mammograms. Case finding above this rate usually reflects the incidence seen in an unscreened or underscreened population. Over the study period, the incidence rate encountered in the population screened by self-referral mammography was more than 4 per 1000 half the time, suggesting lack of a completely effective screening process in the population (Figure 3).

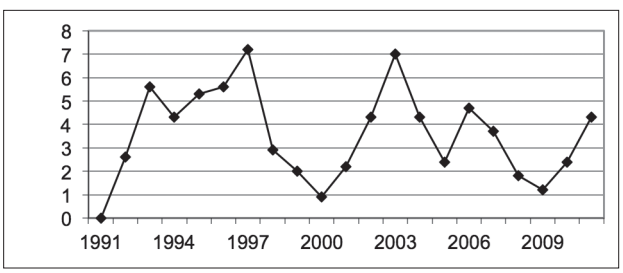

Figure 3. Rate of breast cancer in self-referral mammography population per 1000 mammograms: 1992-2011.

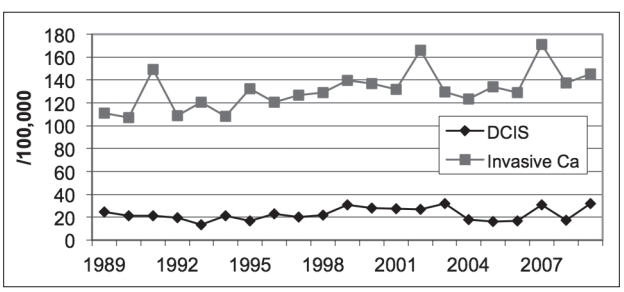

Figure 4. Tumor registry age-adjusted breast cancer rates per 100,000 population: 1989-2009.

Ca = cancer; DCIS = ductal carcinoma in situ.

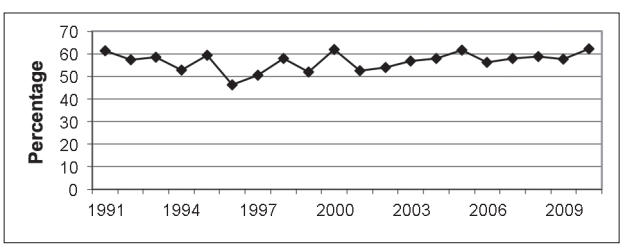

Figure 5. Percentage of screen-detected breast cancers: 1991-2010.

During the last two decades, the annual total number of patients with breast cancer has increased. The incidence rates reflect a moderate increase predominately in the invasive breast cancers, with minimal change in the noninvasive cancer rates (Figure 4). The intermittent peaks in incidence rates of 1991, 2002, and 2007 may reflect the initiatives introduced at those times: self-referral mammography development; adoption of HEDIS measures; and introduction of EMR-supported Panel Support Tool and Best Practice Alert, respectively.

Screen-Detected versus Symptomatic Cancer

Historically, the presence of a breast mass led to the diagnosis of cancer. With the expectation that mammography would identify cancers before they were clinically evident (ie, absence of mass, nipple discharge, pain, or skin changes), mammography screening expanded. Compared with the prescreening era, the most common breast cancer presentation now in the surgeon's office is a patient with no palpable findings and a pathology report from a biopsy performed by radiologists. Between 1985 and 1989, the nonpalpable presentation rate increased from 22% to 58% because of mammographic screening expansion. Even though there has been a further increase in screening since 1989, the nonpalpable cancer rate has been 60% for the last 20 years (Figure 5).

Influence of Self-Referral Mammography on Stage

Screen-detected cancers in women age 40 to 80 years demonstrated a lower stage at presentation on average for all age groups compared with the unscreened patients (Figure 6). There was no stage shift noted between groups using the self-referral mammography process or clinician-initiated screening. The convenience of the self-referral mammography option has therefore allowed a larger percentage of women at risk to be screened without detracting from the desired outcome of early detection, and is now used by half of the women undergoing the screening process (Figure 7).

Overall, the stage distribution of breast cancers detected by screening in women with a family history of breast or ovarian cancer did not appear to differ significantly from that seen in the screen-detected cancers in women of average risk (Figure 8). However, in our data for Stage IIA (T2, N0-N1, MO)[3] a statistically significant difference ($p < 0.05$) was noted with a greater number of high-risk patients presenting at this stage compared with women of average risk. This finding may suggest the need for an enhanced screening process for high-risk women, or possibly reflect a difference in underlying biology and time course of disease.

Discussion

Since 1983, screening for preclinical breast cancers has been the domain of mammography. The opportunity to identify a cancer years before it is a palpable mass has transformed treatment and improved survival. Detection of cancers at an early preclinical stage is dependent on having a sensitive and specific screening test that is acceptable to patients, has reasonable cost, is convenient, and can be performed on an identifiable population at risk. Over the years since 1983, many women have felt unsure how to proceed, because different recommendations

have been made over time by specialty societies, cancer management organizations, and guideline expert panels.

Early attempts to increase mammography screening in the community relied on mobile mammography units and small self-referral programs. For decades, these efforts only reached a small segment of the population[4] or served only limited geographic areas.[5,6] Concerns about patient selection,[7,8] patient compliance, follow-up, clinical breast examination, legal exposure,[9] and costs have hampered the mobile community outreach efforts, making them impractical for the population at large.

Overcoming these challenges was also required in the managed care population served by KPNW as we integrated a self-referral mammography process throughout our facilities. How does an organization make population-based screening more effective? Our first effort through the self-referral mammography program in 1991 was designed to reach inward to allow women who were coming to our clinics for other reasons to initiate screening without having to go through a process initiated by their primary care providers. This step proved to be convenient for women and helped our overburdened primary care physicians meet the need for preventive care more efficiently. The addition of the Safety Net program in 1995 supported an outreach program to women who were not being screened through self-referral mammography or clinician office-based care. The goal of our effort was to reach the underserved by identifying their risk status and inviting participation. The combination of these processes proved to be popular with women, and an ever-increasing number used the self-referral mammography option for their care.

Further substantial increases in self-referral mammography use corresponded to initiatives subsequently implemented: HEDIS (2002); Panel Support Tool (2006); Best Practice Alert (2008); and interactive phone calls, letters, and birthday cards (2008). The use of performance metrics associated with HEDIS provided a clear impetus for the delivery infrastructure to improve in the second decade. Corresponding to the increasing use of self-referral mammography for scheduling, the percentage of cancers detected through the self-referral mammography process has increased substantially.

The HEDIS measures continue to show that an increasing number of screening examinations are being done. It is unclear why the percentage of cases found through screening does not show a corresponding increase in screen-detected cases. We have previously reported on our screening program for colon cancer.[10] In that report, we found that an increasing number of endoscopic screening examinations did not correlate with more effective detection of asymptomatic cancers. Population effectiveness appeared to correlate with high rates of screening in the population at risk, not the number of tests performed per se. With the screen-detection rate being steady at 60% for 20 years, we could improve screening effectiveness by examining the screening patterns of the patients presenting with symptomatic disease.

Most patients who have a family history of breast or ovarian cancer do not have a genetic abnormality and are frequently reluctant to consider a genetics assessment. The identification, education, and counseling of this group is frequently complicated by emotional reluctance about the "knowing." Although radiologists have taken the patient's family history into consideration when interpreting breast images and have consistently recommended annual mammography, an in-office process with genetic risk information in the mammography suites may be useful. On closer inspection, the in-office and outreach efforts for the patients with a family history are predominately passive. Given their current workloads, expecting the primary care providers to add another responsibility by adding this dimension to their workload is impractical.

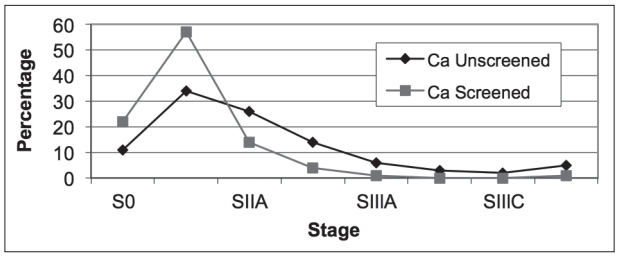

Figure 6. Impact of breast cancer screening on cancer stage in women age 40 to 80 years: 1992-2010.

Ca = cancer.

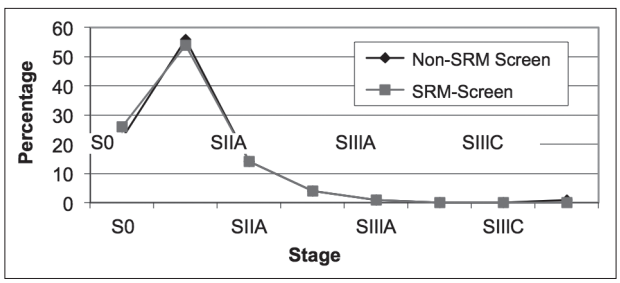

Figure 7. Impact of self-referral mammography screening (SRM) on breast cancer stage in women age 40 to 80 years: 1992-2010.

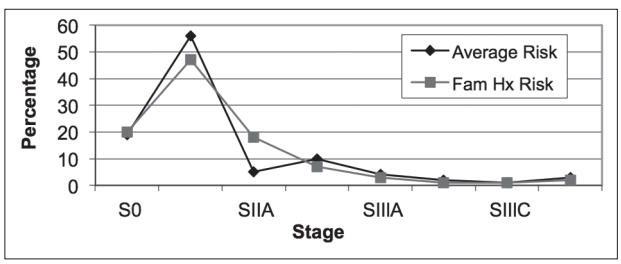

Figure 8. Impact of breast cancer risk on cancer stage between women at average risk and those with a family history of breast or ovarian cancer (high risk): 1991-2010.

Hx = history.

Conclusion

During the last 20 years, more than 995,000 mammograms have been completed in the KPNW Region, with more than 8752 new breast cancers diagnosed. Experience with self-referral mammography in a large prepaid health care program has not been previously described, to our knowledge. Our efforts to provide breast cancer screening to our "unattached" patients has been

successful. Over time, the self-referral mammography process has transitioned into the preferred scheduling process for half of our population.

With an understanding of the whole process, planners introduced a series of in-office and outreach programs to ensure greater screening.[11] Continuous reengineering of the care process has been the most important element of our history, demonstrating how an increasingly complex set of patient care needs and clinical situations can be integrated and tracked to ensure optimal outcomes, freeing clinicians from overwhelming demands on their time. The role and impact of the self-referral mammography program on the overall breast cancer diagnostic process has been reviewed, including the impact on breast cancer stage. It is clear by the lack of change in the screen-detection rate that further targeting may improve outcomes. We have previously reported the KPNW experience of system innovation in colon cancer screening during a 30-year period and have appreciated the need for detailed examination of data to be sure the right questions are being asked, when some of the expected results are not met.

As clinicians, health insurers, and policymakers have used indirect measures to rate an organization's performance, it is critical to ask the additional questions:

a. Is there a system that supports a guideline-based screening?
b. Is there a system to identify high-risk patients?
c. Is there a process to regularly review the outcomes we expect?
d. Are we overscreening or underscreening women based on their personal risk?
e. What is the screen-detection effect on the high-risk patients versus the average-risk population?
f. Are there systems to support better active surveillance?
g. Do we reach out to those individuals who may not be aware of their need to be screened?

We have summarized the evolution of our process from a passive clinician-controlled testing program to an active, complex, comprehensive screening system. Our success has been because of the collaborative efforts of our leadership, providers and registry staff, and members who all became engaged in and benefited from these efforts. ❖

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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Superfluous Residue

Cancerous tumors develop with greatest frequency in the breast of women … .
Such unnatural tumors have their source in the black bile, a superfluous residue of the body.

—Galen of Pergamon, 130 AD-200 AD, Greek-speaking Roman physician, surgeon, and philosopher