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Evaluating Population-Based Screening Mammography Programs Internationally

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Abstract

This report describes the purpose and activities of the International Breast Cancer Screening Network (IBSN), a voluntary consortium of countries that focuses on collaborative research to identify and promote efficient, effective approaches to breast cancer control world-wide through population-based screening mammography. Sponsored by the U.S. National Cancer Institute, the IBSN was established in 1988 with eleven participating countries. By 2005, membership had grown to 27 countries. Recent IBSN efforts have involved gathering information on program organization and quality assurance activities, evaluating measures and methodologies for assessing screening mammography performance and outcomes, and examining the information that programs are providing to women as a means of facilitating informed decision-making about the benefits and risks of screening mammography. The ongoing IBSN effort demonstrates that—despite marked differences in health care systems—international collaborative work can contribute new knowledge to the monitoring and evaluation of organized, population-based screening mammography programs, and identify potential areas for improvement in screening performance in practice.

Keywords

breast neoplasms; mammography; mass screening; population-based

Introduction

Evidence in the mid-1980s from eight randomized controlled trials demonstrating that mammography reduced breast cancer mortality by 30% led to the development and implementation of population-based screening mammography programs in many countries. Sweden, Iceland, Canada, the Netherlands, the United Kingdom, and Finland all initiated organized, population-based programs in the mid- to late 1980s, and at least 19 other countries have done so subsequently (1). Whether these programs can realize mortality reductions comparable to those demonstrated in randomized trials is an active area of investigation. Several countries have begun to assess the effectiveness of their screening mammography programs, and some have demonstrated a mortality benefit equivalent to or greater than that of the trials (2–4). In others, however, the magnitude of the effect appears to be smaller (5–9). A major methodological challenge in these evaluations is the difficulty in determining the

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extent to which the mortality benefit may be due to screening, or to treatment, especially since there have been major advances in breast cancer treatment following the completion of the mammography trials. Because of the need for long-term data in assessing the mortality impact of a breast cancer screening program, evaluation of the effectiveness of screening mammography outside of randomized controlled trials will be an ongoing activity (10).

Implementing, monitoring, and evaluating an organized screening mammography program is a complex undertaking. There should be a systematic means of identifying and inviting the target population, and delivering a high-quality, technically proficient examination. Moreover, screening outcomes—including the quality of radiological interpretation—must be monitored. Comprehensive data on all aspects of the screening process—from identification of the target population to diagnosis of breast cancer—are required. In December 1988, representatives from eleven countries that had implemented or planned to initiate population-based breast cancer screening programs convened in a workshop to discuss the potential for cross-national efforts to assess screening mammography diffusion and effectiveness (11). This workshop led to the establishment of the International Breast Cancer Screening Network (IBSN).

Overview of the International Breast Cancer Screening Network

The IBSN is a voluntary consortium of countries that have active, population-based screening mammography programs or—as in the case of the United States—mammography registry systems (12). These programs can be national or subnational in scope, and established or pilot-based. Sponsored by the U.S. National Cancer Institute, the IBSN has grown from eleven participating countries in 1988 to 27 countries in 2005. As can be seen in Table 1, nearly three-quarters of the countries are located in Europe, with the remainder in North and South America, the Middle East, and Asia/Pacific. The mortality data presented in Table 1 also illustrate the salience of breast cancer as a public health issue in these countries.

The initial purpose of the consortium was to generate a common database for the evaluation of screening mammography programs, and the consortium's original name—the International Breast Cancer Screening Database Project—reflected this objective. Over time, differences in program organization, procedures, data definitions, and data collection became increasingly evident, and made prospects for cross-national comparisons as well as establishing a common database highly daunting. Therefore, during a consortium meeting in 1997, the group decided to shift its focus from creating a common database to collaborative efforts aimed at understanding how to use and compare data from screening mammography programs internationally, and developing methodologies for evaluating the impact of population-based breast cancer screening programs. In keeping with this realignment of purpose, the group also changed its name to the International Breast Cancer Screening Network (IBSN).

Each country that participates in the IBSN is represented by one individual, generally an epidemiologist or senior data analyst who is actively engaged in evaluating the screening program. The consortium meets biennially, and is co-chaired by a representative of the U.S. National Cancer Institute and two country representatives, each of whom serves in a co-chair capacity for four years. Ideas for collaborative projects are discussed at the biennial meetings, and those that have the support of a majority of the country representatives are moved forward through small working groups. As of 2005, six working groups have been formed to undertake projects in program assessment, quality assurance, performance evaluation, mortality evaluation, and communications. Each of these efforts is described in more detail in the sections that follow.

Program Assessment

An early IBSN working group was established in an effort to document and better understand the characteristics of the diverse screening programs in the consortium's member countries. The Program Assessment working group undertook two surveys to obtain information about screening program organization, target populations, coverage policies, funding, service delivery, and outcomes ascertainment. The first survey was conducted in 1990, with nine countries participating, and the second in 1995, with 22 countries participating. Results, which were summarized in two publications (1,13), demonstrated variability in the age ranges and proportion of the target population covered by screening programs, as well as in the detection methods and types of facilities used for screening. Differences in procedures for recruitment, taking and interpreting mammograms, and notifying participants of results also were noted. With the recent and rapid diffusion of Internet technology, the IBSN has moved its program assessment effort to a Web-based database for periodically updating information on the screening programs represented in the consortium. Table 2 summarizes characteristics of breast cancer screening programs in 19 IBSN countries that participated in the most recent update, conducted in 2002. Selected information from the program assessment effort also is made available on the IBSN Web site (<http://appliedresearch.cancer.gov/ibsn/>).

Quality Assurance

Quality assurance—defined as a system of procedures, checks, audits, and corrective actions to ensure that health services and reporting activities are of the highest achievable quality—is critical to realizing optimal screening program benefit (14). Mammography is a complex radiologic procedure, and when it is of poor quality, it may result in the failure of the screening program to achieve the mortality reductions demonstrated in controlled settings. It may also lead to such adverse consequences as missed cancers, increased false positive examinations, higher costs, and anxiety and discomfort for women who undergo additional diagnostic procedures. A major objective of quality improvement in screening is to ensure cancer detection while maintaining a low rate of false positives, thereby reducing use of diagnostic evaluation for women who do not have cancer. Because of the importance of quality assurance to screening program outcomes, the IBSN established the Quality Assurance working group in 1998. This group undertook an assessment of the scope of quality assurance activities for screening mammography across IBSN member countries.

For this assessment, a comprehensive questionnaire was developed and mailed in May 1998 to IBSN representatives in the 23 countries participating in the consortium at that time. The questionnaire focused on several aspects of screening mammography quality assurance, including: organization of quality assurance; site visits and accreditation; technical quality control; quality assurance for data systems; quality assurance in follow-up and treatment; and program performance and impact measures. Twenty-two countries responded to the request for quality assurance information, and results were summarized in four publications that described and compared countries' organization of and external requirements for screening mammography quality assurance; technical quality control; quality assurance for data to evaluate screening mammography program performance; and quality assurance in treatment and follow-up (15–18).

Overall, the assessment demonstrated a high level of attention to quality assurance among IBSN countries, with programs implementing a broad array of mechanisms to enhance the performance and quality of screening mammography. It also afforded insight into the cross-national comparability of screening mammography data. Updated information on IBSN countries' quality assurance activities will be obtained periodically through the Web-based database mentioned in the previous section. Table 3 provides summary information about the

quality assurance requirements reported by 19 IBSN countries that participated in the 2002 update; comparison of these results with the 1998 assessment shows minimal change in legal, accreditation, inspection, and guideline requirements. It also highlights the challenges associated with assessing screening program mortality impact, with nearly two-thirds of IBSN countries relying at least in part on a linkage to cancer registry outcomes data that is not automated. In addition to the four published articles from the 1998 assessment, selected information from the quality assurance effort can be found on the IBSN Web site (<http://appliedresearch.cancer.gov/ibsn/>).

Mortality Evaluation

Whether population-based screening mammography programs are contributing to reductions in breast cancer mortality is a central question in the evaluation of screening programs. In the fall of 1999, the IBSN established the Mortality Evaluation working group to assess the current use and future development of methodologies to evaluate the impact of population-based screening mammography on breast cancer mortality and related outcomes. This working group has identified several challenges in evaluating breast cancer mortality. These include the rarity of breast cancer death as an outcome (i.e., the 10-year survival rate is approximately 50%); the random variation in yearly death rates; quality issues in cause of death determination; changes in cause of death classification; changes in the effectiveness of treatment over time; and the complexity of distinguishing the separate contributions of screening and treatment to mortality reductions.

To date, the working group has examined trends in incidence and mortality over time in several European countries. Methods for assessing breast cancer mortality that have been discussed by this group include calculating a refined mortality rate, which requires linkage between cancer and cause of death registers, and examination of breast cancer deaths for cases that were diagnosed after the screening program was introduced. Poisson regression and case-control comparisons are other approaches that are being utilized (19–22). The group plans to evaluate stage distribution data as well as how specific aspects of screening program organization influence breast cancer mortality in separate analyses. A particular challenge facing the working group is that large sample sizes are needed for stable estimates, and many programs do not have sufficient sample sizes, especially given the need for incorporating potential changes in screening and treatment that may have occurred over time. Finally, program differences in defining such key terms as the proportion of the target population covered, proportion of women in the target population who are invited to screening, and opportunistic screening contribute to difficulties in making cross-national comparisons.

Performance Evaluation

Because screening programs must be operational for ten years or longer before it is possible to evaluate their impact on breast cancer mortality in the target population (10), programs also have focused on assessing intermediate measures of performance. Although international variation in such screening mammography performance measures as the recall rate, positive predictive value of screening, and positive predictive value of biopsy have been documented (23–24), factors contributing to this variation are not well understood. In an effort to enhance understanding of variation in specific intermediate measures of screening program performance, an IBSN Performance Evaluation working group was formed in the fall of 1999. An initial project undertaken by this working group involved a multi-part process for gathering data from IBSN countries to assess and compare program recall rates, positive predictive value of the screening test, and cancer detection rates. Results indicate that program differences in screening mammography practices as well as a lack of standardization in defining and gathering data on recall and positive predictive value make international comparisons of these

performance measures problematic, even though similar patterns of relationships among these measures were observed for most countries (25).

In addition, the group is examining how countries define and measure the interval cancer rate. The interval cancer rate is important because it is an indicator of screening program accuracy, and can lead to program adjustments in the length of the screening interval or in quality assurance activities. cursory comparisons of interval cancer rates in the published literature show considerable variation across programs and countries (26). Because of differences in the age ranges and time periods as well as in the inclusion criteria for interval cancers represented in this literature, it is not clear to what extent meaningful comparisons can be made across different programs and countries. The ongoing IBSN Performance Evaluation working group effort will be able to shed light on this important question. A current activity of the group involves describing how different programs and countries identify and classify interval breast cancers (27).

Communications

A new meta-analysis of data from three of the eight screening mammography trials that showed no significant mortality benefit after 13 years of follow up was published in 2001 (28). This controversial study, along with the release in 2002 of revised guidelines by the U.S. Preventive Services Task Force in which screening mammography was given a grade “B” recommendation (29), has prompted screening programs in several countries to develop or revise the messages and decision aids they provide to women in their target populations to more fully inform them of the benefits and risks of mammography. A new Communications working group was established during the May 2002 biennial meeting of the IBSN for the purpose of identifying and encouraging “best practices” in communicating information about screening mammography, and developing communication materials that member countries could tailor for use in their specific populations. This working group has obtained existing informational materials and decision tools from member countries, and compared the various information strategies internationally (30,31). The group also developed a ‘how-to’ manual on designing communications tools for cancer screening that provides an overview of how issues in informed decision making might be addressed within the context of written materials (32).

Conclusions and Future Directions

Since 1998, the International Breast Cancer Screening Network (IBSN) has fostered information-sharing and collaborative efforts aimed at enhancing the monitoring and evaluation of population-based screening mammography programs internationally. The ongoing activities of this consortium in documenting and comparing diverse approaches to implementing complex breast cancer screening programs and assessing their performance and outcomes is contributing to our understanding of effective service screening delivery. As these programs mature, opportunities for comparative analyses of performance measures and mortality impact will increase. Moreover, the considerable knowledge base that has been developed for screening mammography programs within this consortium will be of benefit not only to newly-established screening mammography programs, but may also contribute to the design and implementation of other types of population-based screening. As the interests and responsibilities of many IBSN members have evolved to also encompass colorectal and cervical cancer screening, the consortium was expanded to include these additional types of cancer screening and renamed the International Cancer Screening Network (ICSN) in May 2006.

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Table 1

Age-adjusted annual breast cancer mortality rates in 1994–1998 for 25 countries, organized by region of the world, participating in the IBSN

Region/Country	Annual breast cancer deaths per 100,000
Europe	
Belgium	26.4
Denmark	29.2
Finland	17.9
France	21.4
Germany	23.7
Greece	16.7
Hungary	25.3
Iceland	36.8
Ireland (Republic)	25.8
Italy	20.7
Luxembourg	23.2
Netherlands	27.8
Norway	20.7
Portugal	18.4
Spain	18.1
Sweden	17.5
Switzerland	25.2
United Kingdom	26.8
North America	
Canada	22.7
United States	21.2
South America	
Uruguay	26.3
Middle East	
Israel	26.2
Asia/Pacific	
Australia	19.7
Japan	7.7
New Zealand	25.9

Source: World Health Organization. Rates are adjusted to the WHO world standard population.

Table 2
 Characteristics of breast cancer screening programs in 19 IBSN countries responding to a survey in 2002.

Region/Country	Program Type	Year Program Began	Detection Methods	Age Groups Covered by Mammography	Screening Interval in Years	
					Age 40–49	Age 50+
<i>Europe</i>						
Denmark	State/provincial/regional	1991	MM	50–69	NA	2
France	National, with regional implementation	1989	MM; CBE	50–74	NA	2
Iceland	National	1987	MM; CBE	40–69	2	2
Italy	National, with regional implementation	2000	MM	50–69	NA	2
Luxembourg	National	1992	MM	50–69	NA	2
Netherlands	National	1989	MM	50–74	NA	2
Norway	National	1996	MM	50–69	NA	2
Portugal	State/provincial/regional	1990	MM; CBE; BSE	45–64	2	2
Spain	State/provincial/regional	1990	MM	45–69	2	2
Sweden	State/provincial/regional	1986	MM	40–74 ¹	1.7	2
Switzerland	State/provincial/regional	1999	MM	50–69	NA	2
United Kingdom	National	1988	MM	50–64	NA	3
<i>North America</i>						
Canada	National, with provincial implementation	1988	MM; CBE ²	50–69	NA	2
United States	Mammography registry system	1995	MM; CBE	40+	1–2	1–2
<i>South America</i>						
Uruguay	National	1990	MM; CBE; BSE	40–64	1	1
<i>Middle East</i>						
Israel	National	1997	MM	50–74	NA	2
<i>Asia/Pacific</i>						
Australia	National, with state implementation	1991	MM	50–69	NA	2
Japan	National	2002	MM; CBE	50–69	NA	2
New Zealand	National	1998	MM	50–64	NA	2

¹ In half of the countries, the lower age limit is 40 years. In the other half, it is 50 years.

² In 5 of 12 programs.

IBSN = International Breast Cancer Screening Network

MM = mammography

CBE = clinical breast exam

BSE = breast self exam

NA = not applicable

Table 3 Screening mammography quality assurance requirements reported by 19 IBSSN countries responding to a survey in 2002.

Region/Country	Required by Law (type of law and year enacted)	Mammography Facilities Undergo Accreditation	Mammography Facilities are Inspected	Program uses Quality Assurance Guidelines	Screening Program Data are linked to Cancer Registry Data
<i>Europe</i>					
Denmark				Yes	Yes, computerized
France	Yes (National 1999)	Yes	Yes	Yes	Yes, manual
Iceland		Yes	Yes	Yes	Yes, computerized
Italy		Yes	Yes	Yes	Yes, computerized
Luxembourg		Yes	Yes	Yes	Yes, manual
Netherlands	Yes (National 1997)	Yes	Yes	Yes	Yes, computerized
Norway			Yes	Yes	Yes, computerized
Portugal			Yes	Yes	Yes, manual
Spain	Yes (National 1996)		Yes	Yes	Yes, computerized and manual
Sweden	Yes (National 1990)	Yes		Yes	Yes, computerized and manual
Switzerland	Yes (National 1997)	Yes	Yes	Yes	Yes, computerized and manual
United Kingdom			Yes	Yes	Yes, computerized and manual
<i>North America</i>					
Canada		Yes		Yes	Yes, computerized and manual
United States	Yes (National 1992)	Yes	Yes	Yes	Yes, computerized and manual
<i>South America</i>					
Uruguay			Yes		Yes, computerized
<i>Middle East</i>					
Israel		Yes	Yes	Yes	Yes, computerized
<i>Asia/Pacific</i>					
Australia		Yes	Yes	Yes	Yes, computerized and manual
Japan	Yes (Subnational 2000)	Yes		Yes	Yes, computerized and manual
New Zealand			Yes	Yes	Yes, computerized and manual