Appendix 1 (as supplied by the authors): Materials shared with participants

Appendix to: Tripp L, Abelson J. Supporting women at average risk to make informed decisions about mammography when there is no “right” answer: a qualitative citizen deliberation study. *CMAJ Open* 2019. DOI:10.9778/cmajo.20190102. Copyright © 2019 Joule Inc. or its licensors

Included in this appendix are the materials shared with participants. These materials included (in order of use/presentation)

1. **Written information package on the evidence**

2. **Breast Cancer Screening: Making Sense of the Evidence (Public Talk)**
Presentation by a Radiation Oncologist and a Family Doctor on the emerging evidence on mammography screening and its impact on practice

https://www.youtube.com/watch?time_continue=1&v=-jH92dFKgds

3. **PowerPoint Presentations**

McMaster University

Participant Workbook

Eliciting Citizen Values about Breast Cancer Screening

A PROJECT LED BY DR. JULIA ABELSON
PROFESSOR, MCMASTER UNIVERSITY

Funded by the Government of Ontario through a Ministry of Health and Long-Term Care Health System Research Fund grant entitled Harnessing Evidence and Values for Health System Excellence

Participant Workbook

The aim of this workbook is to:

- Provide you with information about the topic that we will be discussing at the upcoming citizen panel meeting – breast cancer screening.
- Explain what we know and don't know about breast cancer screening.
- Encourage discussion about breast cancer screening.

A range of views and perspectives are included in the booklet. These have been collected from scientific studies, media and other sources. Not all possible perspectives are included in the booklet, and you may have ideas of your own that have not been presented. We hope you'll bring these ideas to the panel meeting.

Whenever you see a word in **bold** in the booklet, you can find its meaning on page 14.

Why discuss breast cancer screening?

Breast cancer screening is a complex topic. Health care providers, policy makers, ethicists, patients, interest groups and researchers have been debating the pros and cons of breast cancer screening for many years. There are many questions that don't have easy answers. There are also many views on these questions. Some are provided in this workbook. Others will be presented at the information session and at the citizen panel meeting.

Our goal is to gather citizen values and perspectives about breast cancer screening by:

1. Providing neutral and balanced information about breast cancer screening.
2. Talking about breast cancer screening with people from different backgrounds, with different opinions, needs and expectations.
3. Using knowledge, insight and experience to share information with policy makers about breast cancer screening that reflect your views.

Overall we hope to provide the information you need and the right conditions for you to learn and participate in meaningful discussion with your fellow panel members.

Citizen Panel

The panel you are participating in consists of women from the Toronto region who completed a survey through AskingCanadians and expressed interest in coming together to discuss breast cancer screening. Each of you brings a unique perspective to this issue, and has your own experiences with cancer screening and breast cancer. We look forward to respectful, informative conversations.

MEETING OBJECTIVES

There are 4 main questions that will guide our discussions during the panel meeting. These include:

1. What are the citizen and patient values that should be reflected in breast cancer screening programs?

2. What principles should guide the development of materials to support informed decision making about breast cancer screening?

3. What should be included in government-sponsored information materials about breast cancer screening?

4. Given the shifting nature of the evidence about breast cancer screening, how should information be presented about the risks and benefits of breast screening?

MEETING AGENDAS

TIME	AGENDA ITEM
6:00 pm	Welcome and Introductions • Review of agenda • Consent process • Ice breaker activity
6:30 pm	Dinner is served
6:50 pm	The science of breast cancer screening – introduction to the evidence
7:00 pm	VIDEO: Breast cancer screening: Making sense of the evidence (Public Talk)
8:00 pm	Q & A with Dr. Jonathan Sussman, Radiation Oncologist
8:45 pm	Review of key information & wrap-up

TIME	AGENDA ITEM
9:00 am	Panel members arrive, light breakfast is served
9:15 am	Welcome • Review of meeting agenda • Ice breaker activity
9:30 am	Review of the evidence on mammography screening and group discussion
10:00 am	Incorporating social and ethical values into the discussion
10:45 am	**BREAK**
11:00 am	Supporting informed decision-making about breast cancer screening
12:00 pm	**LUNCH**
12:45 pm	Tools to support informed decision-making: Introduction to small group work
1:00 pm	Small group work
2:00 pm	**BREAK**
2:15 pm	Report back from small group work
2:45 pm	Policies to support informed decision-making
3:30 pm	Wrap up & survey

BREAST CANCER SCREENING

Breast cancer develops in the cells of the breasts. The vast majority of cases are found in women, but it can also occur in men although vary rarely (less than 1% of all breast cancers occur in men). It is estimated that in 2015 9,800 Ontario women were diagnosed with breast cancer, and 1,900 women died from it [1]. Breast cancer is the most commonly diagnosed cancer in Canadian women and is the second leading cause of cancer deaths among women, after lung cancer. During their lifetime, 1 in 9 women is expected to develop breast cancer and 1 in 30 is expected to die from it [1].

Cancer screening involves testing people who are well and do not have any symptoms, to look for early signs of caner. Screening cannot stop people from getting cancer, but it aims to find people who have cancer so they can receive a diagnosis and start treatment.

Screening mammography is the main tool used in breast cancer screening. This test uses x-rays to make images of the breast. Mammography is also used for diagnostic purposes, after a woman or her physician identifies a symptom of the disease such as a lump. The focus of our panel meeting discussions will be on the use of mammography for screening purposes only. **Mammograms** are read by a **radiologist** to determine if any abnormalities are present. If the screening mammogram shows an abnormality, additional testing may be needed which could include **diagnostic mammography, ultrasounds or biopsies** [2, 3].

Screening Guidelines

Screening guidelines are developed for a variety of screening tests, including screening mammography. Screening guidelines are developed by groups of experts who come together to review the scientific evidence available for a specific screening test, and to make recommendations based on this evidence about who should be screened and how frequently. These groups exist worldwide. In Canada, the main source of guidelines for primary care providers is the **Canadian Task Force on Preventive Health Care**. In 2011, the Task Force released new breast cancer screening guidelines. For women who have an **average risk** of developing breast cancer, the Task Force recommends:

- 40 – 49 years: Routine screening mammography is <u>not</u> recommended
- 50 – 74 years: Screening every 2 -3 years is recommend.
- Over 75 years: Discuss the benefits and risks with a health care provider.

Within these guidelines, the Task Force highlights that while mammography can lead to small reductions in the **mortality rate**, patients and physicians must be aware of the risks of screening including the harms associated with **false positives** and **overdiagnosis** when making screening decisions [4]. These harms are discussed in more detail below.

The Canadian guidelines are consistent with those of similar organizations in the United States and United Kingdom, as well as the Canadian Cancer Society.

Provincial Cancer Screening Initiatives

Population-wide breast screening programs have been around for several decades. All provinces and all territories (except for Nunavut) have organized breast screening programs that offer mammography screening to women within their target populations. All programs offer screening to women aged 50 to 74 at least every two years. Quebec and Newfoundland and Labrador require women over 70 years to have a referral from their doctor to participate. In some programs, women are eligible to participate before age 50 and after age 74, though often a physician's referral is needed. Some programs also offer screening more frequently [5].

The Ontario Breast Screening Program

Cancer Care Ontario (CCO) is the Government agency in Ontario responsible for cancer services from prevention and screening through diagnosis, treatment, recovery and end of life care. CCO's Department of Prevention and Cancer Control runs the province's integrated cancer screening program, which provides eligible Ontarians with screening for breast, cervical and colorectal cancer. The **Ontario Breast Screening Program (OBSP)** is part of the integrated cancer screening program. It has been in place since 1990 to provide breast cancer screening to Ontario women within the target population.

Through the OBSP, average risk women aged 50 – 74 with no symptoms of breast cancer have access to a screening mammogram every other year. In some specific cases, women are recalled annually. In this case, average risk refers to women who do not have a personal or family history that would increase their risk of breast cancer, and whose risk of developing breast cancer is similar to those of the same age.

OBSP also offers screening to **high-risk** women; however, very few women fall into this category – in Ontario, only 1% of women meet the criteria for high risk [6]. These criteria include: (1) a **genetic mutation** related to breast cancer is

identified in the individual or her close family members; (2) a woman's risk of breast cancer as determined by a **genetic counselor** is greater than 25%; or, (3) the woman received **radiation** to the chest before age 30 (this refers to radiation for cancer treatments, not the radiation you would be exposed to if you had a chest x-ray). These women are offered more intensive screening starting at an earlier age. Given that the majority of women in Ontario are at average risk for breast cancer, this will be the focus of our discussions. We will not be discussing breast cancer screening for women who are at high risk.

For an average risk woman, the screening process involves the following:

(1) she receives an invitation letter from the OBSP inviting her to participate in screening; (2) she books an appointment with one of 176 OBSP affiliated sites across the province for screening mammography; (3) if the mammogram is normal, she receives a letter with the results in the mail and her physician is informed. If the results are abnormal, she is contacted by her physician or the OBSP to discuss next steps; and (4) one to two years later she receives a letter from the OBSP reminding her to book her next mammogram.

Women over age 74 can make a personal decision to be screened, and can access this screening through the OBSP with a referral from their physician, but they will not be automatically recalled to screening. Average risk women under 50 years old are not eligible to participate in the OBSP. These women are encouraged to speak with their physician about the benefits and risks of mammography. Women who have symptoms of breast cancer, a personal history of breast cancer or breast implants are not eligible to be screened through the OBSP, and access mammography screening through their physicians.

Women in Ontario can receive mammograms through non-OBSP facilities with a referral from their physician; however, the majority of mammograms in Ontario are completed through the OBSP program. In 2012-13, 59% of Ontarian women aged 50 – 74 years had a mammogram in the last two years. Of those women, 76% of them had their mammogram through the OBSP [7]. A key goal of the OBSP is to increase breast screening rates. The target is for at least 70% of the eligible population to complete at least one screening mammogram within a two-year period [8]. They aim to achieve this by aggressively promoting screening to the public, and using technology supports to help primary care providers promote screening.

RISKS AND BENEFITS OF MAMMOGRAPHY

Like any screening test, mammography has both risks and benefits. On the benefits side, screening can reduce a woman's risk of dying from breast cancer. Mammograms can identify cancer early when it may be easier to treat, and this reduces the number of individuals who die from breast cancer. For women between 50 and 69 years of age, the risk of dying from breast cancer is 1 in 155 among women who do not participate in screening, compared to 1 in 196 who participate in regular screening.

With these benefits, there are also risks associated with mammography screening. These include false negatives, which occur when a mammogram shows no signs of cancer, even though cancer is present. **False negatives** are more common in women who are young, have dense breasts or have specific types of fast growing cancers. Cancer can also develop between mammograms. These "**interval cancers**" develop after a woman's mammogram comes back normal, but before she goes back for her next screening. Interval cancers are more common in younger women with dense breasts [9]. In 2009, 13.9% of women who were diagnosed with breast cancer within a year of having a mammogram through the OBSP did not have their cancer detected by the program [8]. On the other hand, mammograms may show something that looks **abnormal,** raising concerns about cancer but further diagnostic testing (mammograms, ultrasounds, biopsies) reveals that the individual does not have cancer [10]. These false alarms are called "false positives". **False positives** occur more frequently when women start having mammograms at an earlier age as they have more mammograms over their lifetime and therefore more chances to have a false positive [11]. In 2010, for every 200 average-risk women who were screened, 16 women had an abnormal mammogram. Of those, 1 had cancer, and 15 were false positives [8]. The majority of individuals (>90%) in Ontario found out within 5 – 7 weeks if their abnormal result was cancer or not [8].

One of the concerns raised about mammography screening has to do with its overall impact on breast cancer deaths. While screening has led to a consistent increase in the detection of cancers at an early stage, this has not corresponded with the same decline in the diagnosis of late-stage (more advanced) cancers or in overall mortality. Early detection through screening is picking up some cancers that might never spread or go on to be life-threatening. Scientists have labeled this "overdetection" or "**overdiagnosis**". Overdiagnosed cases are breast

cancers that, had they not been discovered, would not have presented clinically (through symptoms or a lump) during an individual's lifetime and would not have been life-threatening [10, 12, 13]. As a result, if an individual had not presented for screening they may have never known they had breast cancer. This occurs as some cancers grow very slowly, or not at all. When a cancer is identified through screening there is no way of knowing if the cancer is one that will be harmful or not. As a result, all cancers are treated and some women will receive treatment for cancers that would not have caused them any harm [10, 13] and face the risks that come with treatment without any of the benefits [14]. In the UK's screening programmes (run by the National Health Service (NHS)), 99% of women who are diagnosed with breast cancer as the result of screening will have surgery, and about 70% will undergo radiation treatments and hormone therapies [15]. The unnecessary investigations and procedures that are associated with the detection of these non-life-threatening cancers can be associated with considerable psychological, physical and economic costs.

Answering the question of how many women face false positives and how many women are overdiagnosed is not simple. The more times a woman undergoes mammography screening, the more likely she is to have a false positive. The risk of having a false positive after going for 10 screening mammograms has been found to range from 20% to 60% [16, 17]. The number of false positives can vary based on the radiologist reading the mammogram. Some radiologists may have a lower threshold for asking for additional testing than others [16].

Experts generally accept that overdiagnosis occurs as a result of mammography screening, but they do not agree on how often it happens [18]. Estimates of overdiagnosis can differ depending on the people included in studies and how the study is carried out [14]. The Independent UK Panel on Breast Cancer Screening estimated that about 19% of breast cancers diagnosed in women who went for screening were overdiagnosed [10]. Another large review of many studies on the subject estimated that 30% of cases were overdiagnosed, but the authors acknowledged that this may be an underestimate [17]. Overall, estimates of overdiagnosis vary from less than 5% to over 50% of cases [19].

INFORMED DECISION MAKING

Given that there are both risks and benefits of screening mammography, there is no 'right' decision about whether women should be screened, or not [20]. Screening guidelines provide insights into what the evidence suggests might be

most appropriate; however, guidelines suggest that the recommendations be personalized to the individual patient. Some strategies that could be used to support informed decision making are highlighted in this section.

Primary care physicians

Primary care physicians play an important role in supporting informed decision-making. Screening guidelines encourage health care providers to engage with women in informed decision making regarding breast cancer screening [4, 21, 22]. Informed decision-making means patients are aware of their individual risk of breast cancer, they understand the risks and benefits of screening and they consider their personal values, beliefs and preferences when making a decision [19, 23]. Once the screening decision has been made, the individual should feel they participated in the decision making process as much as they wanted to [23].

Studies suggest that patients making decisions regarding screening would like to do so with the input of their health care provider [21, 24, 25]. Some studies have reported that when individuals do discuss cancer screening with their physicians, the physician will often emphasize the benefits over the harms of the screening tests [26]. A survey conducted with women 40 – 44 years prior to their first mammogram found that only 7% of women reported their physicians discussed the harms of mammography screening with them, where 47% reported their physicians discussed the benefits [21].

Primary care practitioners have access to information on their patients' screening activities through a number of reports. Cancer Care Ontario provides primary care practitioners with a monthly online Screening Activity Report (SAR) that provides, among other things, the breast screening rates for their patients (% of eligible patients who received screening mammograms within the past 2 years) and a list of patients who are eligible for screening. Health Quality Ontario, an arms-length agency of the government of Ontario that is responsible for reporting on the quality of the health care system, provides primary care practitioners with a "Primary Care Practice Report". This report provides information about how patients within a practice are using the health care system, including the number of women aged 53 – 76 years who had a mammogram within the past two years. Understanding screening rates can be a useful tool in primary care settings. Primary care physicians working under certain pay models also receive bonuses from the provincial government based on their screening rates for eligible patients.

Decision aids

Decision aids such as pamphlets, videos and web-based tools can help individuals to understand the screening options available to them, and their risks and benefits [27]. Decision aids are useful when patients are being asked to make a decision in cases where there is no clear decision that is best for all people. Decision aids describe the options available and the potential benefits and harms of each, allowing individuals to consider how the options fit with their personal values [27]. Decision aids do not replace the need for discussion between patients and care providers, but can serve as a starting point for these discussions [19, 27, 28]. Recently, more attention has being paid to the quality of decision aids. The most useful decision aids present the potential benefits and harms of a screening test in a clear, balanced way [29]. Research has suggested that many of the decision aids that have been developed for mammography have a strong focus on the benefits of screening, but pay relatively little attention to the risks such as overdiagnosis. It has been suggested that this may be due to the uncertainty about the extent of overdiagnosis, that it can be difficult to explain in simple terms or that it may have a negative impact on screening rates [30]. During the panel meeting we will look at examples of the decision aids currently available to women across Canada who are making decisions about mammography screening.

Impact of media and public perceptions

While information about risks and benefits may be one piece of the puzzle to ensure informed decision-making, individuals' decisions are often influenced by what we think is socially acceptable [31]. We live in a culture that is, in most cases, very supportive of screening. Surveys conducted in the US and the UK have demonstrated this enthusiasm – the vast majority think screening for cancer is almost always a good idea (87% of Americans, 88.8% of British) and many wanted to be screened even if it meant they would be overdiagnosed (56% of Americans, 45.4% of British) [32],[31].

The media tends to present the positive sides of mammography screening, presenting stories of women, often celebrities, who have gone for screening, been diagnosed with breast cancer and are now cancer-free. These often celebrate mammography, using emotional appeals to encourage others to go for screening [33]. The risks of mammography screening are rarely presented.

The general enthusiasm for cancer screening in our society can make it challenging to make decisions in a fully informed way. The emphasis on the

benefits of screening, with relatively little emphasis on the potential risks can create an environment where there is a sense that participating in mammography is a given, rather than a choice. Carefully considering how mammography screening should be presented in discussions with the public, and what supports might be helpful to promote informed decision making about mammography may be timely given this climate. Throughout the panel meeting we will discuss these issues. We will aim to reach some agreement about what information would be most helpful for Ontarians as they consider mammography screening, how this information can be most usefully shared and presented, and what the next steps are to make this happen.

GLOSSARY OF TERMS

Average risk: individuals who do not have characteristics which put them at high risk for a disease, and have similar levels of risk to others in the same population.

Benefit: Advantage or improvement resulting from an intervention.

Biopsy: taking a small sample of tissue or cells from the body, mostly with a needle

Breast cancer: group of cells in the breast that grow and multiply abnormally, which can in some cases spread to other parts of the breast and the body

Canadian Task Force for Preventive Health Care: A group of primary care and prevention experts who, with the support of the Public Health Agency of Canada, develop clinical practice guidelines to support Canadian primary care providers in delivering preventive health care.

Cancer Care Ontario (CCO): A provincial organization that advises the Ontario government on cancer and renal (kidney) systems, and on access to care for key health services. Among other responsibilities, CCO implements provincial cancer prevention and screening programs.

Cancer screening: the process of testing individuals for cancer when they appear to be healthy and have no symptoms of the disease in order to identify cases when the disease is in an earlier stage and can be more effectively treated.

Diagnostic mammography: x-ray of the breast done to evaluate abnormalities seen or suspected on a prior screening mammogram, or abnormalities identified in the breast such as a lump, pain, thickening, nipple discharge or other unexplained changes.

False negative result: normal tests result in a person with cancer (the cancer is missed)

False positive result: an abnormal test result in a person who does not have cancer (a false alarm)

Genetic mutation: problem in a gene that may increase the risk of certain diseases

Genetic Counselor: individuals with advanced training in genetics who can review a patient's family history and genetic testing results to provide information to patients on their risk of disease.

High risk: individuals are categorized as being 'high risk' if they have specific characteristics (family history, exposure to radiation, etc.) which make them significantly more likely to get a disease than the general public.

Informed consent: A voluntary choice made by an individual after having opportunities to weigh all possible risks and benefits.

Interval cancer: cancer cases that develop in the time between screenings

Mammogram: An x-ray picture of the breast.

Mortality rate: the number of deaths within a certain population over a certain period of time

Ontario Breast Screening Program (OBSP): The OBSP is a program of Cancer Care Ontario which offers free mammography to women living in Ontario within the target age groups.

Overdiagnosis: Cancers identified as a result of screening which would never have caused symptoms or threatened a woman's life. These cases cannot be identified at the individual level, and as a result all women diagnosed with breast cancer will be treated even if their cancer was not life threatening.

Screening guidelines: guidelines on who should be screened for a specific disease, when and how often based on the best available scientific evidence.

Screening mammography: using x-rays to take images of the breast in order to look for signs of breast cancer in women who have no signs or symptoms of the disease

Radiation: treatment using strong x-rays to kill cancer cells or stop their growth

Radiologist: Physicians who are trained to in the use of imagine techniques in the study, diagnosis and treatment of disease.

Ultrasound: a non-invasive technique in which high frequency sound waves are used to form a two-dimensional image used for the examination and measurement of internal body structures, and the detection of abnormalities

SUPPLEMENTARY RESOURCES

VIDEOS

Cancer Screening 1 – Benefits and Harms - https://www.youtube.com/watch?v=sUn1Eyrf_Zs

Cancer Screening 2 – False Positive Results - https://www.youtube.com/watch?v=uPVKvAuKvR0

Cancer Screening 3 - Overdiagnosis - https://www.youtube.com/watch?v=4A_Y42L0dMc

A series of videos that communicate the trade-offs in cancer screening, presented by Dr. H. Gilbert Welch, M.D., M.P.H., a professor of Medicine at the Dartmouth Institute for Health Policy and Clinical Research and a general internist at the White River Junction VA in the United States.

CANADIAN TASK FORCE ON PREVENTIVE HEALTH CARE

Breast cancer guideline presentation - http://canadiantaskforce.ca/ctfphc-guidelines/2011-breast-cancer/guideline-presentation/

A PowerPoint presentation on the updated mammography screening guidelines

Breast Cancer Screening Factsheet: Risks and Benefits, Age 50 – 69 - http://canadiantaskforce.ca/ctfphc-guidelines/2011-breast-cancer/risks-and-benefits-age-50-69/

A factsheet outlining the risks and benefits of mammography screening for women aged 50 – 69 years.

Breast Cancer Screening – Patient FAQ - http://canadiantaskforce.ca/ctfphc-guidelines/2011-breast-cancer/patient-faq/

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Citizen Panel on Breast Cancer Screening: Information Night

Welcome and Introductions

Citizen Panels

- An innovative way to seek public input on important health issues
- Brings together citizens from all walks of life

Background to the research study

- Breast cancer screening guidelines are being reviewed around the world as research studies are generating new information about the effectiveness of mammography
- Emerging evidence has led to confusion surrounding screening mammography
- Increased focus around the world on informed decision making and the role of citizens in this process

Objectives and funding sources

- The objectives of this project are:
  - to elicit citizen values about breast cancer screening;
  - to explore different options to support citizens in making an informed choice regarding mammography; and,
  - to compare different strategies for engaging citizens to inform future work in this area

- Sources of funding: Government of Ontario through a Health Systems Research Fund grant from the Ministry of Health and Long-Term Care entitled: “Harnessing Evidence and Values for Health System Excellence”.

Consent Form

- Informed consent
  - Required for university-based research activities
  - To ensure that you are fully informed and have provided formal consent to participate

Ice breaking activity

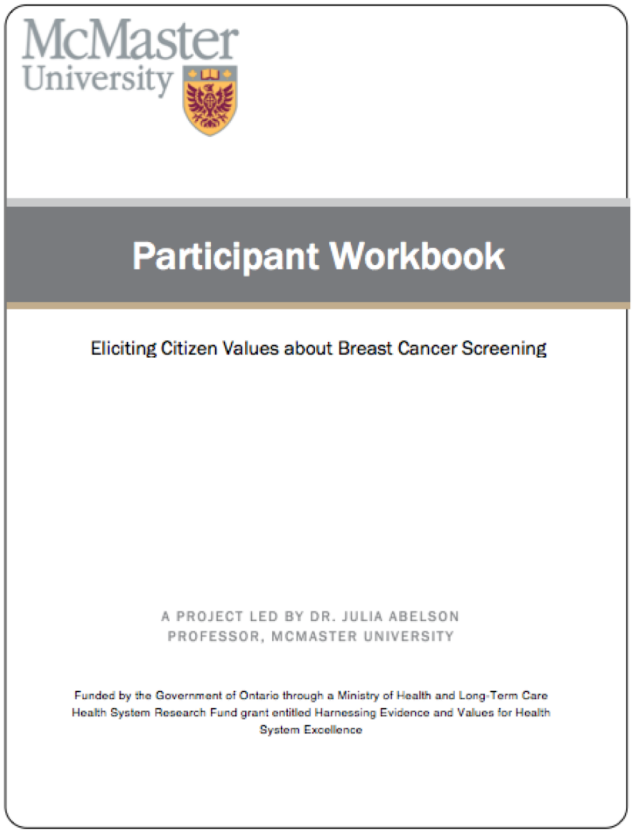
- Introduce yourself
- Tell us why you decided to respond to the invitation from AskingCanadians to participate in this study

DINNER

THE SCIENCE OF BREAST CANCER SCREENING: REFLECTING ON THE EVIDENCE

Sources of Evidence

- Pre-circulated participant workbook
- Tonight's information session

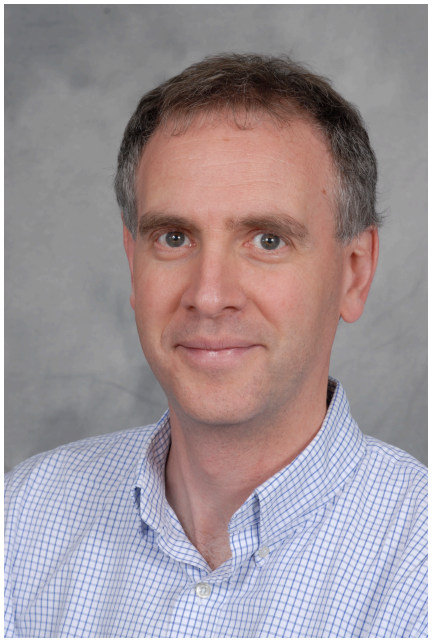


Discussion

- Do you feel like you are well informed about mammography screening? Why or why not?
- Where do you get your information about mammography screening?

Public Talk: Breast Cancer Screening – Making Sense of the Evidence

- Held in March 2015, hosted by the McMaster Health Forum



Dr. Jonathan Sussman
Associate Professor, Department of Oncology, Radiation Oncologist, Juravinski Cancer Centre

Dr. Cathy Risdon
Professor and Associate Chair, Academic, Department of Family Medicine, Family Doctor and Co-Director, McMaster Family Practice

McMaster University

LABARGE Optimal Aging INITIATIVE

McMaster HEALTH FORUM

Breast Cancer Screening:

Making Sense of the Evidence

A Public Talk by Jonathan Sussman and Cathy Risdon
March 25, 2015
McMaster Innovation Park

Discussion

- What are your initial thoughts about the information that was presented during the public talk?
- What surprised you? What felt familiar?

Q & A with
Dr. Jonathan Sussman

Meeting Wrap-Up

- Before Saturday:
  - Please review the information package that you received in the mail, if you haven't already.
  - Review the information materials for Saturday's small group activity
  - Reflect on the information and discussions from tonight. What questions do you still have? What surprised you?

Meeting Wrap-Up

- Saturday's small group activity
  - Review of information materials developed by breast cancer screening programs across Canada
  - You'll receive a package of information tonight with copies of these materials.
  - Please review these before Saturday. When reading them pay attention to the information (what's included, what's missing), the look (cover, how information is presented), and the overall feeling you're left with after reading through it.

Thank you!

See you Saturday at 9am

McMaster University

Citizen Panel on Breast Cancer Screening

March 5, 2016

Toronto, ON

Welcome back!

Research Questions

- What are the citizen and patient values that should be reflected in breast cancer screening programs?
- What principles should guide the development of materials to support informed decision making about breast cancer screening?
- What should be included in government-sponsored information materials about breast cancer screening?
- Given the shifting nature of the evidence about breast cancer screening, how should information be presented about the risks and benefits of breast cancer screening?

A few ground rules…

- Be respectful of each other
- Encourage the active participation of others
- Express your views towards the issues we are discussing openly and honestly
- Challenge others by focusing on ideas
- Keep what is shared in the group confidential

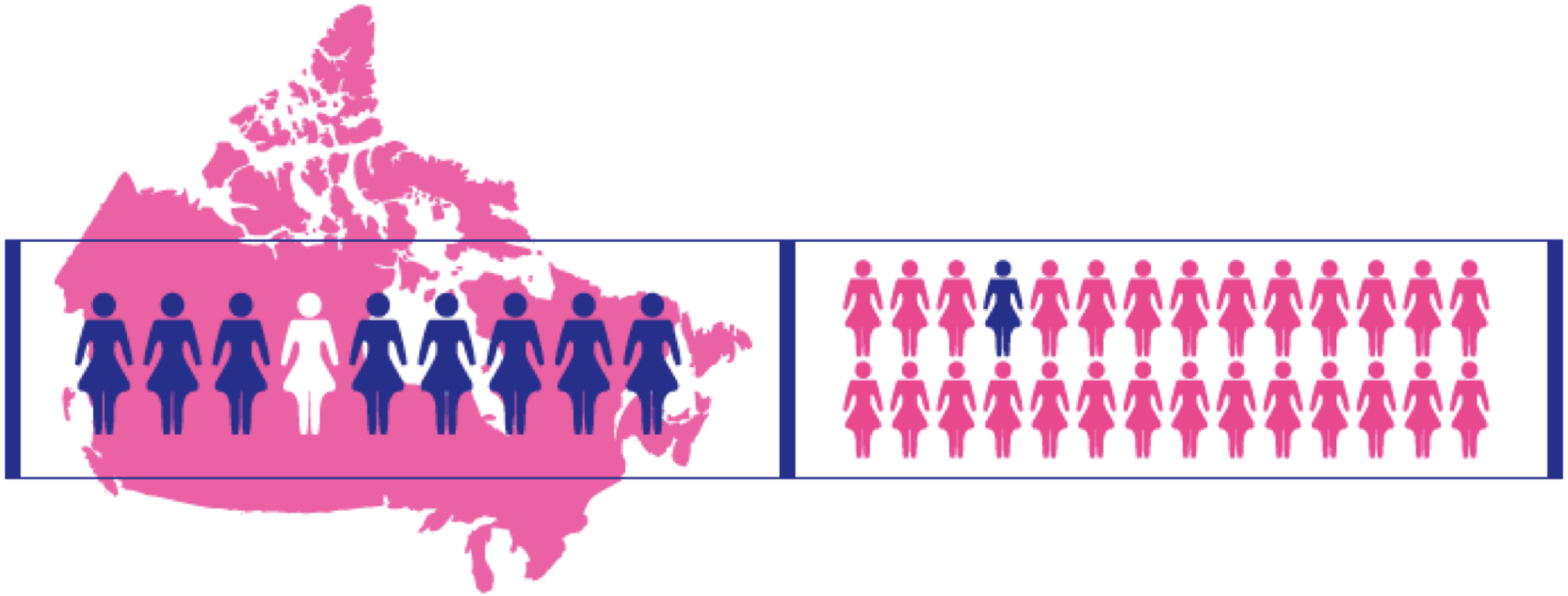
Ice breaking activity

- Think about everything you heard on Thursday night about mammography screening…
- Tell us the following:
  - What did you think was the most important piece of information shared?
  - What was the most difficult idea to understand?
  - What have you thought about the most since then?

THE SCIENCE OF BREAST CANCER SCREENING: KEY MESSAGES

Breast Cancer in Canada

- 1 in 9 women in Canada will be diagnosed with breast cancer in their lifetime
- 1 in 30 women will die of breast cancer.
- Women over age 50 are at highest risk of getting breast cancer – 82% of breast cancers in Canada in 2013 were diagnosed in women over 50.



Average vs High Risk Women

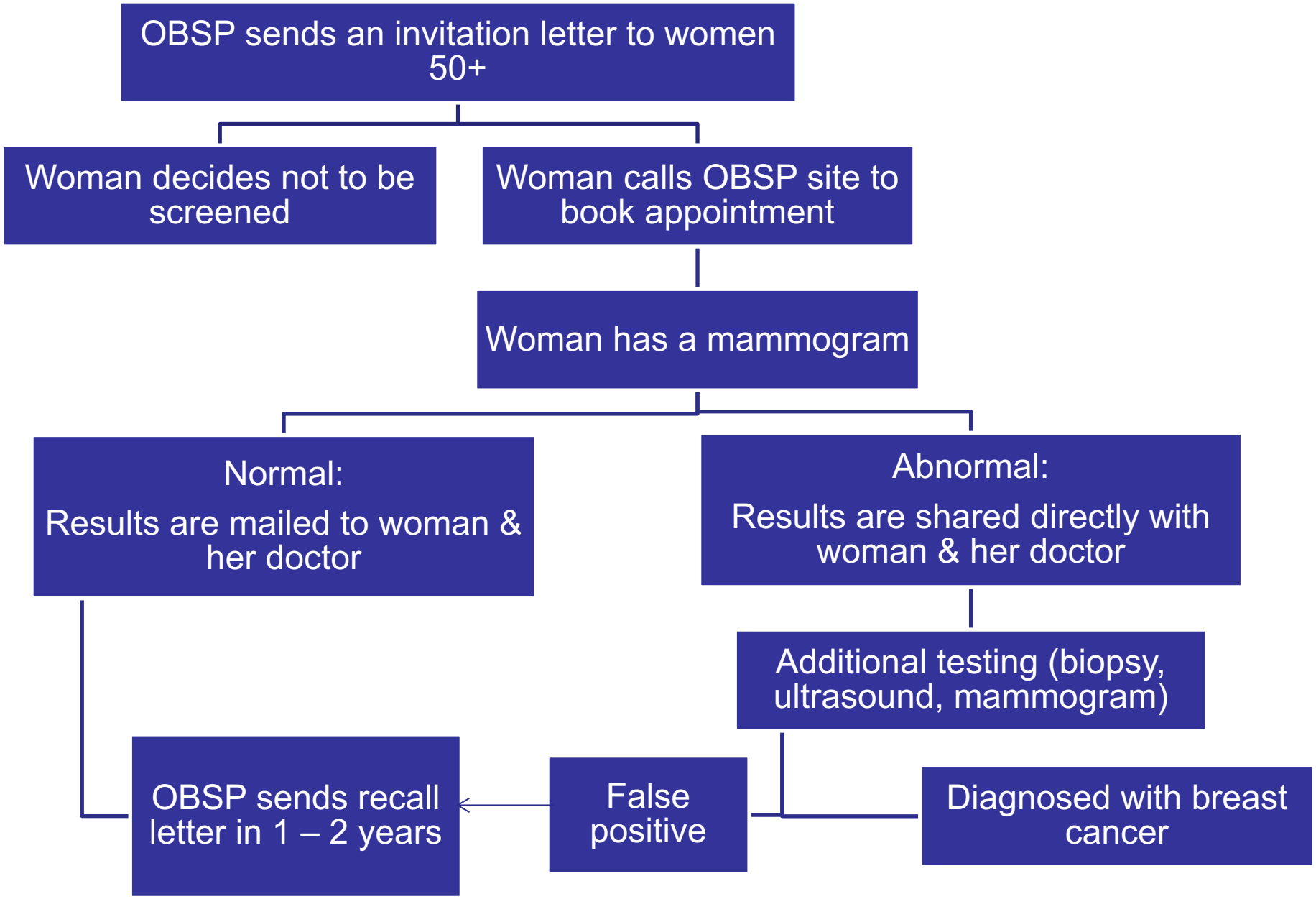
- Focus of our discussion today is on **average risk** women
- Most women are in this category. Less than 1% of women are at high risk for breast cancer
- Examples of women who are at higher risk:
  - Those who have a special gene (BRCA1, BRCA2) which increases their risk, or who have not gone for genetic testing but know their family members are carriers of the gene
  - Had chest radiation prior to age 30 to treat a different type cancer
  - Strong family history of breast cancer and/or ovarian cancer

Breast Cancer Screening in Ontario

Ontario Breast Screening Program

- Population-based screening program
  - Screening is offered to all eligible women in Ontario
- Eligibility criteria for average-risk screening program:
  - 50 – 74 years of age
  - No symptoms of breast cancer (no lumps, etc.)
  - No breast implants
  - No previous breast cancer diagnosis
- Women who are not eligible for screening through the OBSP, or who choose not to participate can access screening outside of the OBSP with a referral from a physician

OBSP Screening Process



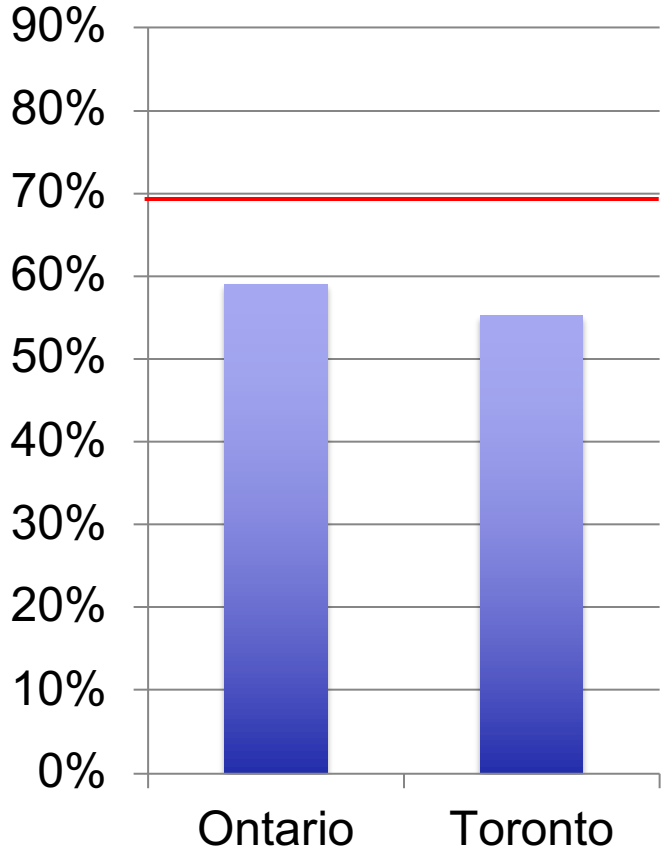
Mammography Screening Rates

Ontario Breast Screening Program

- Aim to screen at least 70% of all eligible women through OBSP
- Current screening rates:

  Ontario: 59%

  Toronto: 55.3%



Risks and Benefits of Screening

Benefits of screening

- Some lives will be saved
- May identify cases of cancer earlier, thereby reducing the treatment burden of the individual

Risks of screening

- False positives
- False negatives
- Unnecessary biopsies
- Overdiagnosis and overtreatment

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Breast Cancer Early Detection

HARDING CENTER FOR RISK LITERACY

by mammography screening

Numbers for women aged 50 years or older who participated in screening for 10 years or more

	1,000 women without screening	1,000 women with screening
Benefits		
How many women died from breast cancer?	5	4
How many women died from all types of cancer?	21	21
Harms		
How many women without cancer experienced false alarms or biopsies?	–	100
How many healthy women were diagnosed and treated for breast cancer unnecessarily?	–	5

Source: Gøtzsche, PC, Jørgensen, KJ (2013). *Cochrane Database of Systematic Reviews* (6): CD001877.
Numbers in the facts box are rounded. Where no data for women above 50 years of age are available, numbers refer to women above 40 years of age. www.harding-center.mpg.de

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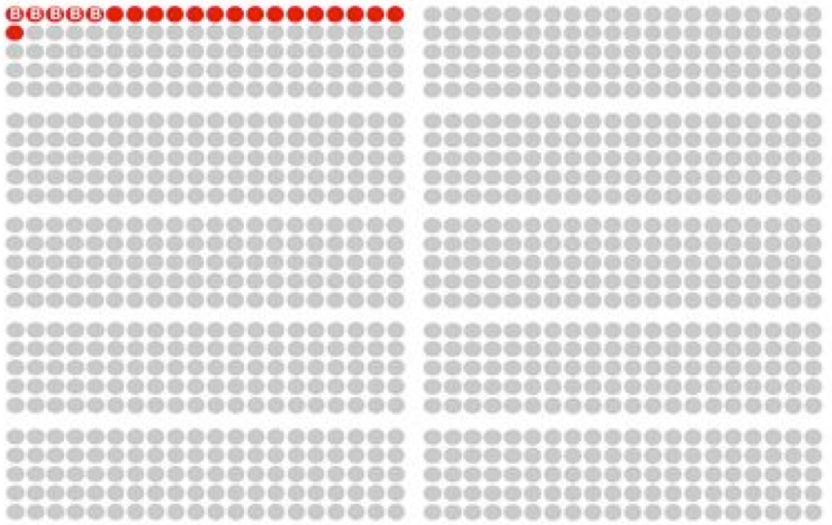
Breast Cancer Early Detection

HARDING CENTER FOR RISK LITERACY

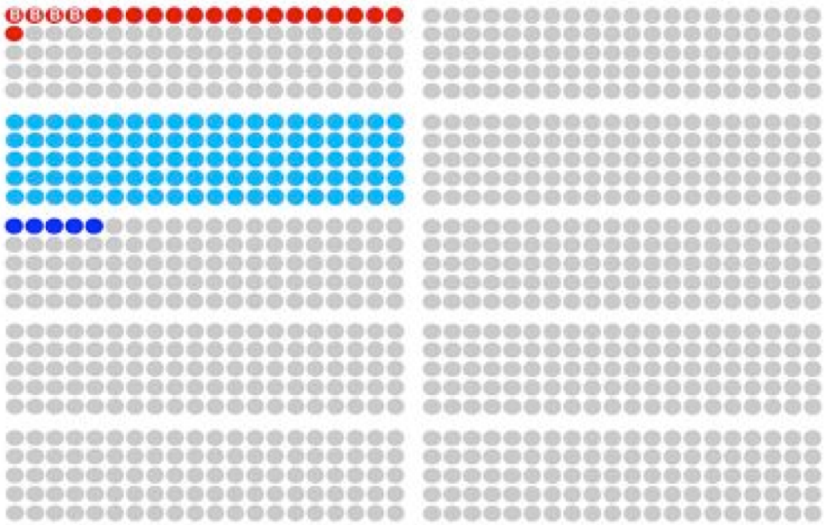
by mammography screening

Numbers for women aged 50 years or older who participated in screening for 10 years or more

1000 women without screening:



1000 women with screening:

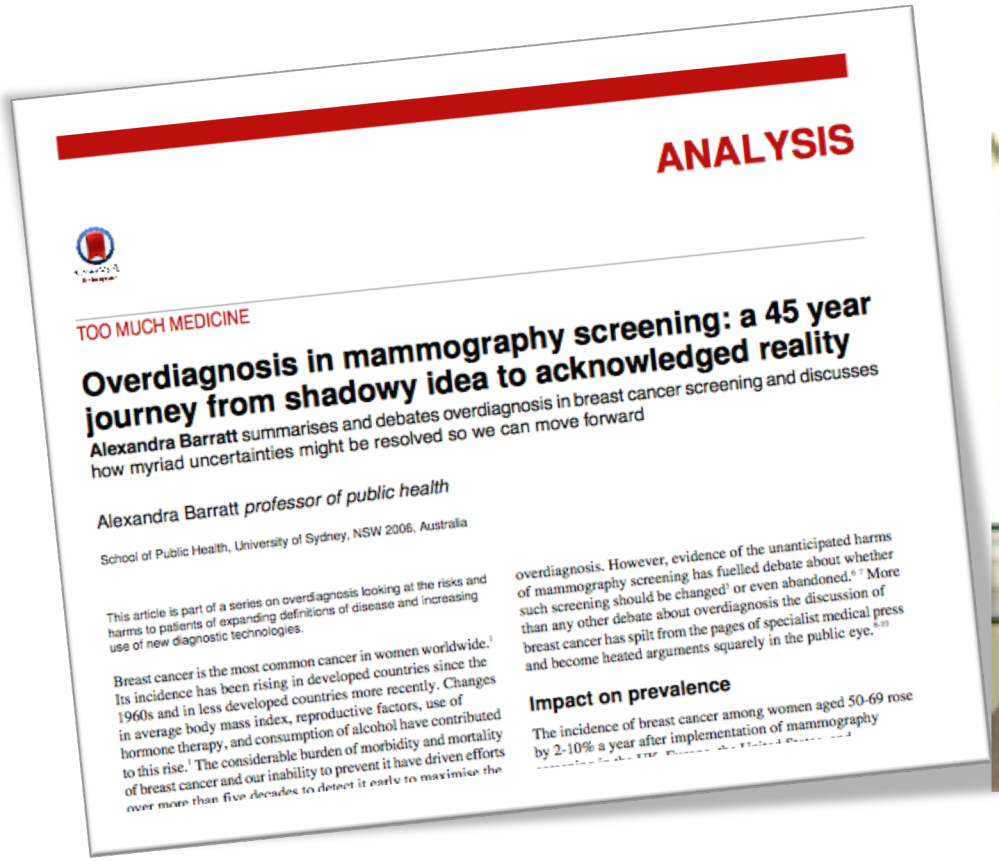


Women who died from breast cancer:	5	4
Women who died from all types of cancer:	21	21
Women who learned after a biopsy that their diagnosis was a false-positive:	–	100
Women who were diagnosed and treated for breast cancer unnecessarily:	–	5
Remaining women:	979	874

Source:
Gøtzsche, PC, Jørgensen, KJ (2013). *Cochrane Database of Systematic Reviews* (6): CD001877
Numbers in the facts box are rounded. Where no data for women above 50 years of age are available, numbers refer to women above 40 years of age.
www.harding-center.mpg.de

There is uncertainty in the evidence…

- A challenge is there are varying estimates of the magnitude of the benefits and risks
- Interview with Dr. Alexandra Barratt from Australia



ANALYSIS

TOO MUCH MEDICINE

Overdiagnosis in mammography screening: a 45 year journey from shadowy idea to acknowledged reality

Alexandra Barratt summarises and debates overdiagnosis in breast cancer screening and discusses how myriad uncertainties might be resolved so we can move forward

Alexandra Barratt *professor of public health*

School of Public Health, University of Sydney, NSW 2006, Australia

This article is part of a series on overdiagnosis looking at the risks and harms to patients of expanding definitions of disease and increasing use of new diagnostic technologies.

Breast cancer is the most common cancer in women worldwide.[1] Its incidence has been rising in developed countries since the 1960s and in less developed countries more recently. Changes in average body mass index, reproductive factors, use of hormone therapy, and consumption of alcohol have contributed to this rise.[1] The considerable burden of morbidity and mortality of breast cancer and our inability to prevent it have driven efforts over more than five decades to detect it early to maximise the overdiagnosis. However, evidence of the unanticipated harms of mammography screening has fuelled debate about whether such screening should be changed[2] or even abandoned.[3–7] More than any other debate about overdiagnosis the discussion of breast cancer has spilt from the pages of specialist medical press and become heated arguments squarely in the public eye.[8–10]

Impact on prevalence

The incidence of breast cancer among women aged 50-69 rose by 2-10% a year after implementation of mammography

TOPIC 1: INCORPORATING YOUR VALUES INTO THE DISCUSSION

What do we mean by Societal Values?

- Broadly shared values in society that relate to the use and impact of health services and programs on its citizens and community members
- Examples:
  - access, quality, choice, resource use, public expectations
- Each of these may be more or less important in relation to different health services and programs

What do we mean by Ethical Values?

- Moral principles or beliefs about how health interventions and programs (such as mammography) should be used
- Examples:
  - Balancing harms and benefits
  - Respect for human rights and dignity
  - Patient consent
  - Autonomy

Some values to consider…

- Quality
- Evidence informed policy
- Effectiveness
- Resource stewardship (sustainability, good use of funds, value for money)
- Resource sufficiency (adequate resources)
- Equity (access to information about screening)
- Solidarity (strong, trusting, compassionate relationships in the health system)
- Population health
- Patient-centred care
- Collaboration
- Shared responsibility for health

Questions for Discussion

Now that you have a sense of what social and ethical values are…

What societal and ethical values should be considered in the design of provincial mammography screening programs?

BREAK

TOPIC 2: SUPPORTING INFORMED DECISION MAKING

What is informed consent?

- Informed consent: making a decision about an activity/action based on the risks and benefits and the individual's own circumstances and beliefs.

- Situations where you may provide informed consent:

  - Medical context: diagnostic tests, treatments

  - Research context: participation in studies such as this one

Questions to consider

As a potential user of a screening test…

- what does it mean to be informed about these tests?
- what does it mean to have choice about these tests?
- what does it mean to consent to these tests?

What role do the values we considered before the break play in informed consent?

Thinking about breast cancer screening, is informed consent important?


EXIT

Questions to consider

What are your initial reactions to this video?

Put yourself in the shoes of the patient in the video…

- Did you have sufficient information to make an informed decision?
- Did they provide too much information? Too little? What questions remain?

Put yourself in the shoes of the physician...

- How would you approach this conversation?
- What would you do differently?

What are decision aids?

- Tools that help people become involved in decision making by…
  - making explicit the decision that needs to be made
  - providing information about the options and outcomes, and
  - clarifying personal values

- Designed to complement counseling from a health practitioner, not replace it

Ideally, decision aids should:

- Describe the condition related to the decision
- Include balanced information about the decision to be made
- Highlight the options available *(which in the case of screening, means to screen or not to screen)*
- Outline what is involved with each option
- Highlight the benefits and risks of each option, in equal detail
- Present information on how likely the risks and benefits are
- Describe the next steps based on test results
- Ask readers to consider their values when making a decision

Challenges…

- Not all decision aids are equal
  - growing critique that many do not provide balanced information on the benefits and harms of screening
- Often distributed by screening programs whose goal is to increase screening rates
- To address this issue a Citizens' Jury was held in the UK in 2012
  - Citizens heard from experts in breast cancer screening and health communications
  - Provided input into the development of a new invitation letter and leaflet for breast cancer screening

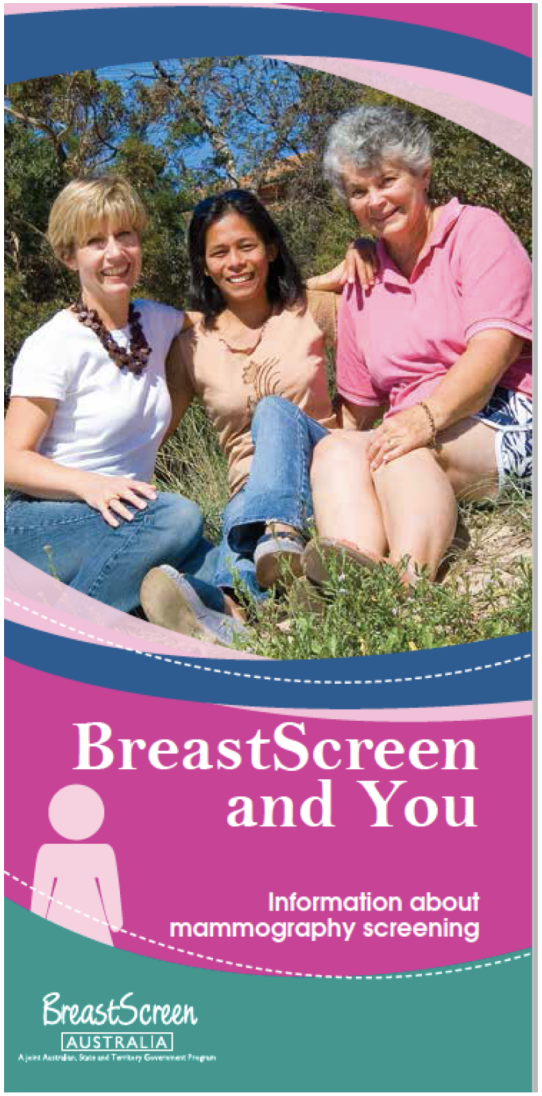
Discussion

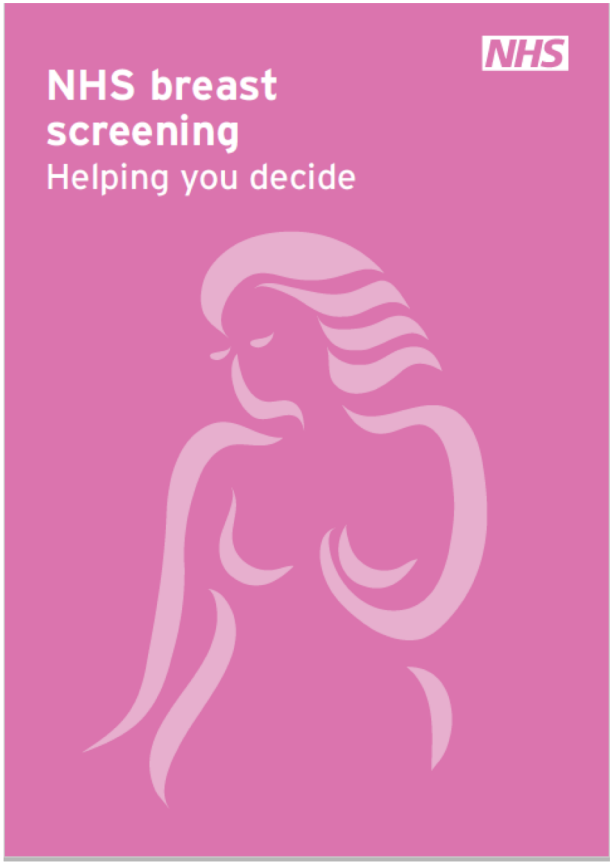
- Have you ever consulted brochures or other materials when trying to make a decision about screening?
  - What were your experiences with these information sources?
- What principles do you think should guide the development of materials to support informed decision-making?

Things to look at in decision aids…

- The way in which decision aids present information can have an impact on how that information is understood
- When looking at decision aids, there's a lot to consider:
  - What is the main message that the decision aid is trying to get across?
  - How is the information presented?
  - What information is included? What information is excluded?

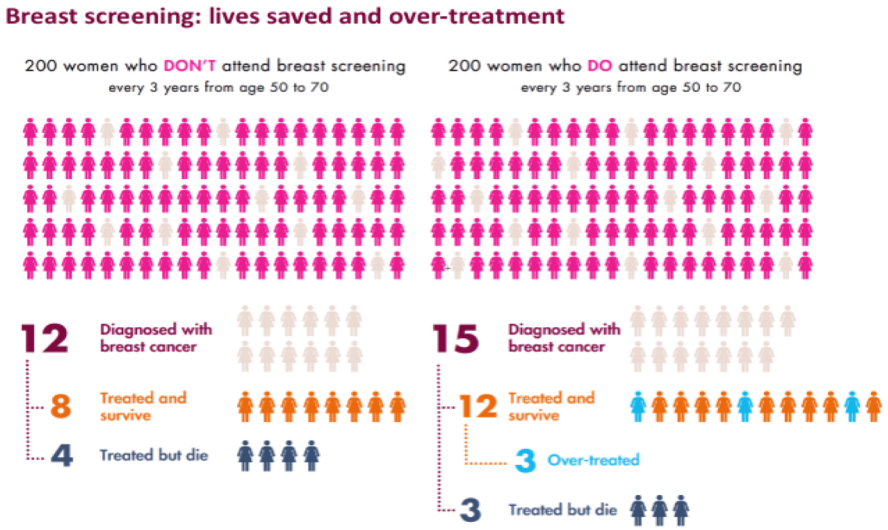
What should the main message be?



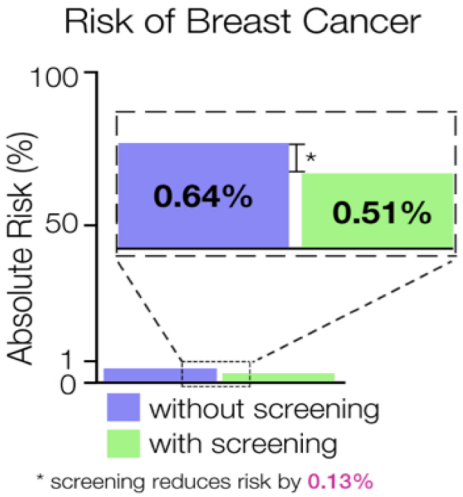


How is the information presented?

Diagrams



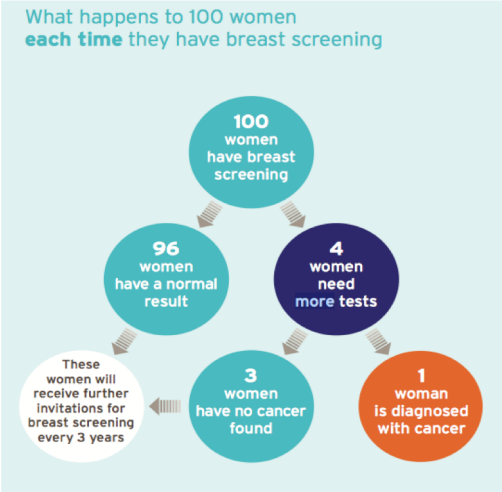
Graphs



Tables

Effects of screening on…	1,000 participants over 20 years	1,000 non-participants over 20 years
…the number of additional tests	495	325
…the number of breast cancers detected	77	54
…the number of deaths due to breast cancer	13	20
…the number of cases of overdiagnosis*	10	0

Flow charts

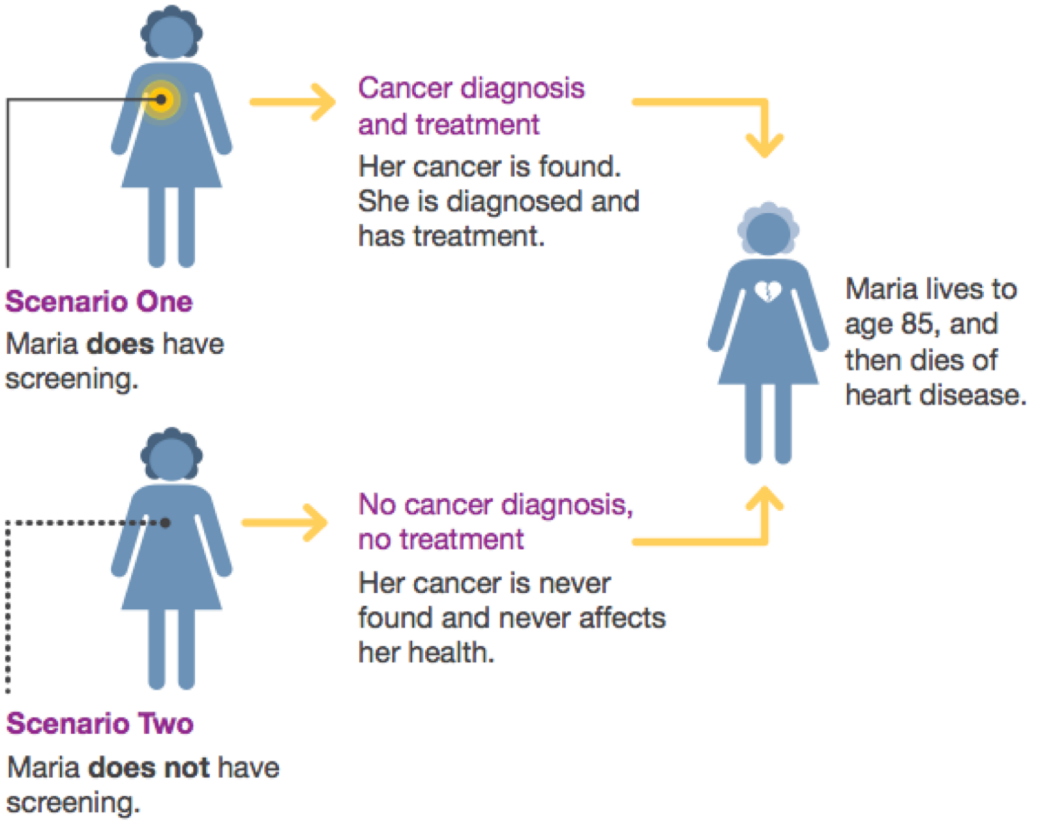


What is the best way to present new concepts?

Words

Overdiagnosis and overtreatment - Some of the cancers and some of the early cell changes (carcinoma in situ) that are found by screening grow so slowly that they would never have developed into a real cancer. Many of these screen-detected "pseudo-cancers" would even have disappeared spontaneously, if they had been left alone, without treatment.

Images



LUNCH

GROUP ACTIVITY: REPORT BACK

TOPIC 2C:
SUPPORTING INFORMED DECISION MAKING: POLICIES

Screening Programs

- Screening programs have two key responsibilities:
  - provide information to support informed decision making
  - promote screening to increase screening rates

Policies to support informed decision-making

- What can be done at a policy level to support informed decision-making about breast cancer screening? Who should be involved in this work?

- How should screening programs balance their obligations to *provide information and choice* to screening program participants, and their interests in *screening as many people as possible* to reduce cancer deaths across large populations?

Meeting wrap-up