



# Public and patient values about informed choice and mammography screening: Results from 4 Ontario deliberations

Julia Abelson, PhD

Professor, Department of Clinical Epidemiology & Biostatistics

Member, Centre for Health Economics and Policy Analysis

McMaster University

Laura Tripp, MA

McMaster University



# Acknowledgements

## ■ Funders

- Government of Ontario
  - Ministry of Health and Long-Term Care Health System Research Fund grant “Harnessing Evidence and Values for Health System Excellence”

## ■ Co-investigators & Collaborators

- Melissa Brouwers (McMaster University)
- Jonathan Sussman (McMaster University)
- Greg Pond (McMaster University)
- McMaster Health Forum

# Background to the study

- mounting evidence questioning the benefits of population-based mammography screening
- screening has not reduced mortality as anticipated
- risks of screening are more apparent (but with uncertainty about their magnitude)
- linked to broader discourse about overdiagnosis and overtreatment

200 women who **DON'T** attend breast screening  
every 3 years from age 50 to 70



**12**

Diagnosed with  
breast cancer



**8**

Treated and  
survive



**4**

Treated but die



200 women who **DO** attend breast screening  
every 3 years from age 50 to 70



**15**

Diagnosed with  
breast cancer



**12**

Treated and  
survive



**3**

Over-treated

# Newspaper Headlines

**Elizabeth Hurley 'bullies' friends into breast cancer screening**

**'Angelina Jolie effect' on breast cancer screening endures**

**Day of the Mammogram aims to screen more women for breast cancer**

**Women urged to book their first mammogram**

**Booking a mammogram takes just minutes and could save your life**

 October 2, 2015 |  Filed under: Health |  Posted by: Press Release

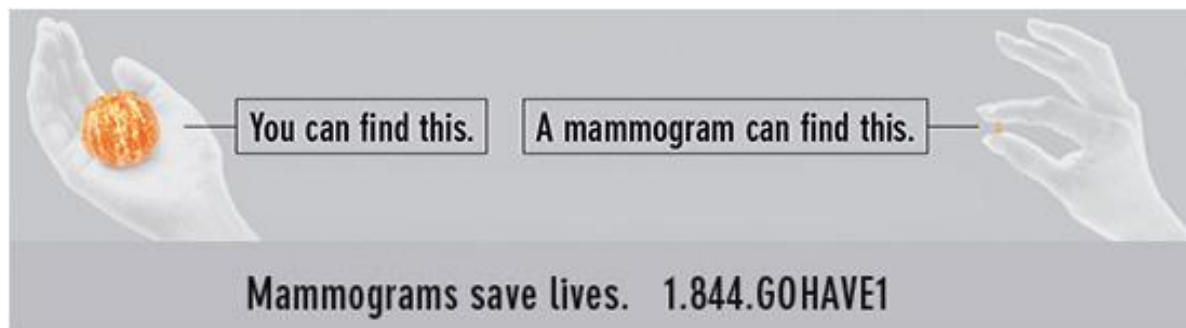
**American Cancer Society says mammograms should be done earlier than in Canada**

By **Lindsey Tanner** The Associated Press

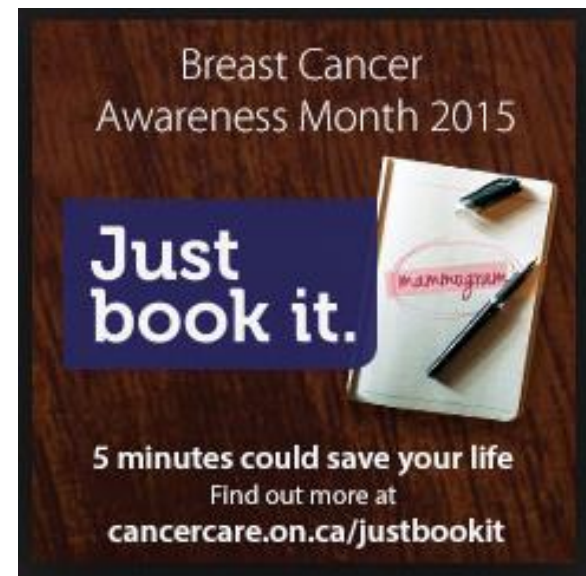
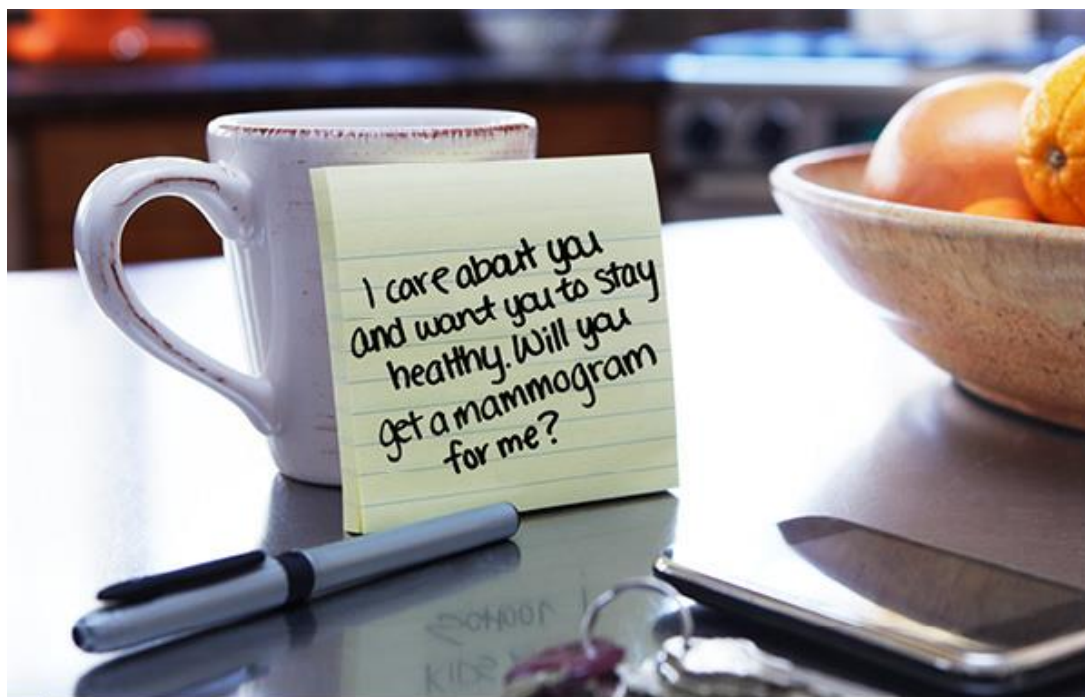
**The Canadian Association of Radiologists continues to support breast cancer screening for women in their 40s**



# Online Advertisements



Canadian Breast Cancer Foundation



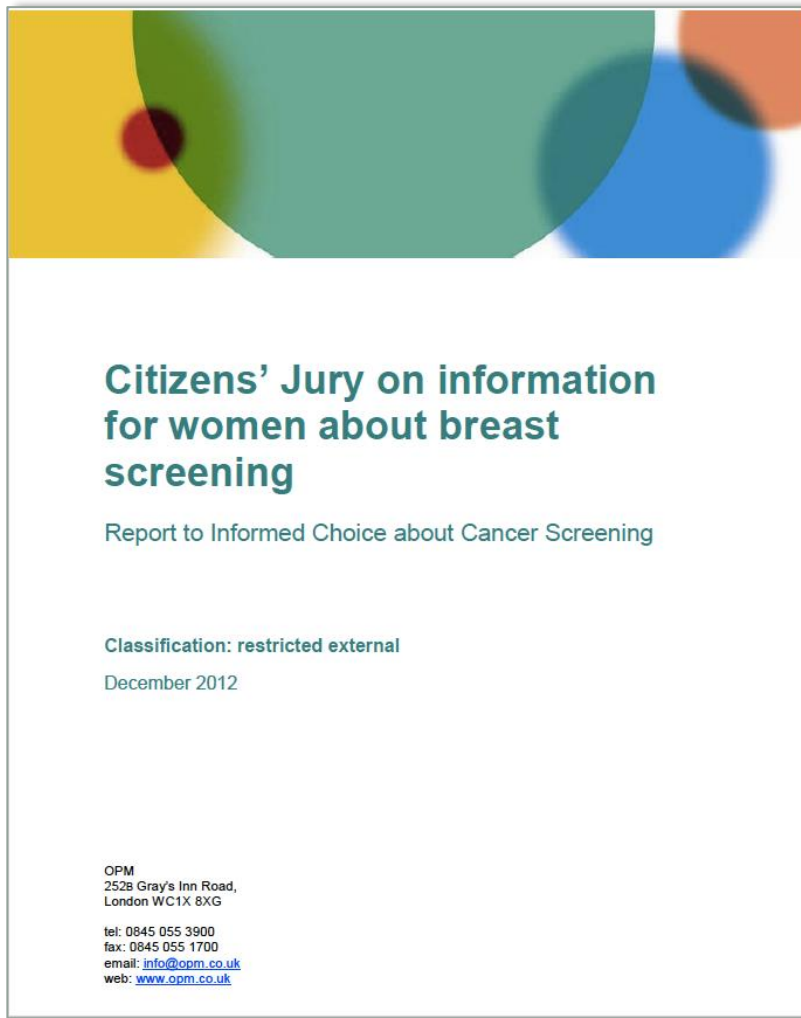
Ontario Breast Screening Program

Cancer screening sees what you can't.  
Find out when it's your time to screen at [ontario.ca/screenforlife](http://ontario.ca/screenforlife)



# What about public and patient perspectives?

- Recent work in Australia & the UK
- Very little in Canada




BMJ

BMJ 2013;346:f158 doi: 10.1136/bmj.f158 (Published 23 January 2013)

Page 1 of 13

## RESEARCH

### Women's views on overdiagnosis in breast cancer screening: a qualitative study

 OPEN ACCESS

Jolyn Hersch *PhD candidate*<sup>1,2</sup>, Jesse Jansen *research fellow*<sup>1,2</sup>, Alexandra Barratt *professor of public health*<sup>2</sup>, Les Irwig *professor of epidemiology*<sup>1</sup>, Nehmat Houssami *breast physician and associate professor and principal research fellow*<sup>1</sup>, Kirsten Howard *professor of health economics*<sup>1</sup>, Haryana Dhillon *research fellow*<sup>2</sup>, Kirsten McCaffery *associate professor and principal research fellow*<sup>1,2</sup>

# Project Objectives

- Elicit citizen and patient values to inform breast cancer screening programs' approaches to informed decision making

## Other project components:

- Population survey of Ontario women's knowledge, attitudes and practices re mammography screening
- Focus groups with primary care providers



# Project description and methods

- Four citizen deliberations convened between March 2015 – April 2016
  - pan-Ontario, men and women 18+ (panel A)
  - Thunder Bay, women of screening age (panel B)
  - Brantford, high screening rates, women of screening age (panel C)
  - Toronto, low screening rates, women of screening age (panel D)
- Total participants: 48 (11-13/group)



# Recruitment

- mix of approaches (opportunity for comparison)
  - ❑ new and returning: online research panel (AskingCanadians) + re-convening from a previous panel (panel A)
  - ❑ online volunteer boards, classified ads, kijiji (panel B & C)
  - ❑ population survey (AskingCanadians) (panel D)

30 Thursday, June 25, 2015

### 53. GENERAL SERVICES

Heated, indoor storage available! Many different sized \$1/square foot for all of our available units. Call FURNITURE RE-CYCLE today 622-1022

Looking to move? Call FURNITURE RE-CYCLE today for professional movers with over 15 years of experience! Senior discount available 622-1022

RJC Window Cleaning Handyman Services. Hedges, pruning, gardening, dump runs, clean dirty siding, eavestrough cleaning. What you need not listed? Call Robert 632-2161.

SPRING CLEAN UPI Monster size trailer! Rubbish removal, we recycle. Part loads, no items too big or too small. Commercial/residential, free estimates. SENIOR DISCOUNTS. 472-6371 or gapace@lakeheadu.ca

TREE REMOVAL SERVICE, from take down to clean-up. In town rural or at the cottage. ++ experience very reasonable rates, free estimates, insured, and seniors discounts. Call 345-4363

TREE REMOVAL SERVICES From cutting to clean up. If you have any trees to be removed, we can take care of it. FREE ESTIMATE 807-632-7000

### 54. HOME IMPROVEMENTS

#1. Specializing in all types of fences: PT. Wood, Ornamental, PVC fences and Cedar & Wood decks. Call Brian @ 628-6937

COMPLETE HOME RENOVATIONS! Floors, siding, decks, bathroom, and kitchen. Free Estimates! Call 639-0268 or www.tecmarthunderbay.ca

Flooring: laminate, ceramic, hardwood, competitively priced and installed by octagon contracting. Call 633-4488 for your free quote.

### 63. COMING EVENTS

#### Participants needed for research study about breast cancer screening

Are you a woman over age 50? Would you like to learn more about mammography screening?


Researchers from McMaster University are looking for 14 volunteers to take part in a study about breast cancer screening. Participants will learn more about the evidence about mammography screening, and have an opportunity to discuss this issue with other women.

Participation would involve attending a meeting the evening of July 22nd in Thunder Bay and completing two short surveys.

Participants will receive \$75.00 in appreciation of their time. Dinner will also be provided.

If you're interested, please visit <https://goo.gl/jh1ZZP> to complete a short eligibility survey, or contact us at 905-625-9140 ext. 22333, [lauratripp@mcmaster.ca](mailto:lauratripp@mcmaster.ca).

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB)




### 73. INFORMATION

#### ANSWER

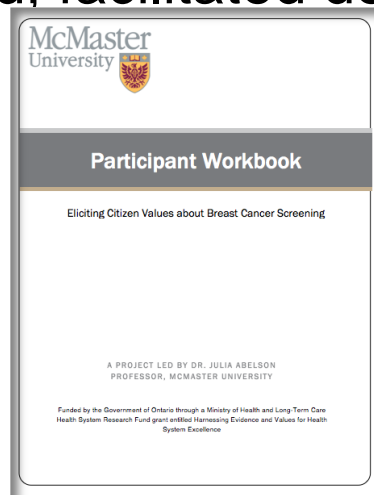
GARB	TASS
ACHE	ASCI
RHEA	REAM
	DOT DAM
GIS	LAC
UCA	TRAS
TAM	GULAR
SLED	SITTA
AM	NUN
RAGOUT	RAS
ABA	CANA
ABT	HEAT
DAN	OLPE

PREVIOUS S and integrity.



# Structure and elements of the deliberations

- Combined evening and full-day deliberations (Panels A, C & D) and 1 half-day deliberation (Panel B)
- Pre-circulated reading material and discussion questions
- Presentation by experts on the evidence about breast cancer screening and its role in primary care (live or pre-recorded)
- Expert available for Q & A following presentation
- Structured, facilitated deliberation in large and small groups



# Deliberation topics

- What citizen and patient values 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 materials about breast cancer screening?
- How should information about the risks and benefits of breast cancer screening be presented?

# **SELECTED RESULTS**

# ***General attitudes toward mammography screening***

- not perceived as a choice by many - just “something you do”
- Seen as the “responsible” thing to do – the “right” thing

*“You just automatically went. Everybody went. Your peers all went.” (Panel A)*

*“I like to think I’m informed. And I just went because I just assumed it was the only way you would know if you got it, and it would be helpful because you would be able to catch it early and early signs and all of that. I had no idea there was another side to it. I had no idea. And I never, ever heard somebody say, well are you sure you want to go? It was just what you did.”*

*(Panel C)*



# ***Knowledge and awareness***

- uniform lack of awareness of the risks associated with screening

*“I hadn’t considered the risks either I just thought it was like taking your vitamins or a vaccination like you said, it was a good thing. (Panel B)*

- palpable reactions to evidence presented by experts – some shock, betrayal and anger that they had not been informed

*“my first reaction to all the information provided...was betrayal that my family doctor did not bring any of this up to me...how can they be telling you yes, go get your mammogram...without ever mentioning all of these things that could happen?... To me it was just mindboggling.”*

*(Panel A)*

# *Valuing transparency*

- Lack of openness from screening programs and health care providers about:
  - the equivocal nature of the evidence about screening
  - incentives for reaching screening thresholds

*“...I wasn’t given any material... It was jaw dropping for me to see that and to be told, that it really doesn’t look like it makes a difference whether you get a mammogram or not.”*

(Panel B)

*“...the other thing that shocked me was the incentive to the doctors...that made me sort of second guess...was I being sent because this is truly what [my doctor] thought was right for me and beneficial long term, or was it because there was, and just in a small respect, this incentive involved as well”*

(Panel A)

# *Valuing information*

- Desire for a more balanced approach to communicating benefits *and* risks
- Access to multiple and consistent information sources
  - Not only through your primary care provider
  - Different languages
  - Common approaches across the country
- Maybe it's better not to know?

*“But the question still exists, if this information was completely drawn out and provided to everyone in the public, does it help limit the confusion and help us with the decision or are we still going to be going to our providers asking for their advice on what to do.” (Panel A)*

# *Valuing the individual vs. the population*

- Making decisions for the population at the expense of the individual

*[Speaker A]“It’s huge and I think in that when the health minister are making all these big choices, I’m not sure if they really look at people as people or as we’re a bunch of numbers. Because if you see it as a person sitting down and it was your wife, or your sister or your niece then that one person would be worth it, you know what I mean? So I think they see that oh 100,000 people here had you know, had overdiagnosis but what about people that*

*you*

*know did go and have the mammogram and were saved and lived.” (Panel B)*

*[Speaker B]“So how do you decide at what point something is valuable?”*

# *Valuing Access with Choice*

- Having access to and the choice to be screened or not is highly valued

*“So knowing that I have access to a screening service is important, but then I want to be able to make that choice about whether that’s actually important to me or not. It may be important to some of my neighbours, and not to me. So just that automatically assuming that because I’m over fifty, I should be doing something like this every two years is not – I don’t value that. (Panel D)*

# ***Empowered or Burdened?***

- more careful thinking about future screening decisions (some said they would not continue)
- acknowledgement of the risks trumped by other concerns (e.g. benefits of early diagnosis and personal experiences with breast cancer)

*“In my opinion, anything that would help me live longer and enjoy my grandkids and the rest of my life, then I say why not. And then maybe not do it every other year, but maybe every few years...” (Panel C)*

- confusion and uncertainty for some

*“That’s what I’ve been thinking about the most...what am I going to do the next time I get a letter...now I really have a lot of questions like should I or shouldn’t I, and that’s...I’d rather it just be black and white. You’ve really raised a lot of questions” (Panel C)*



# Messages for policy makers

- women want to be informed about the benefits *and risks* of mammography screening
- mammography screening should continue to be available to the public
- mammography screening should be framed more clearly as a choice - not something that individuals are expected to do
- screening programs and providers should be transparent about their objectives, the evidence supporting mammography screening and their motivations

ARTICLE IN PRESS

# Delivering Patient-Centered Cancer Screening

## Easier Said Than Done

Tanner J. Caverly, MD, MPH,<sup>1,2</sup> Eve A. Kerr, MD, MPH,<sup>1,2</sup> Sameer D. Saini, MD, MS<sup>1,2</sup>

---

### Integrating Patient-Centeredness With Prevention

Despite a consensus around the importance of both prevention and patient-centeredness, integrating these two concepts into “patient-centered prevention” will not be easy. There are times when decision making about preventive care simply cannot be patient-centered. For instance, policy decisions about whether to reduce the salt content of food products

benefits and harms of screening (a logistic challenge); and

2. informed screening decisions that may go against one's personal preferences and sense of professional obligation (a conceptual challenge).

Patient-centered care has been defined as “care that is respectful of and responsive to individual patient preferences, needs, and values.”<sup>1</sup> Respecting a patient's autonomy and right to choose is clearly necessary for

# Final reflections

- citizen deliberations on personal, contested topics can generate emotional responses, confusion and a sense of unease
- more attention needed to support informed decision making in areas like mammography screening
  - efforts will require time, sensitivity and a range of approaches
- women who are making screening decisions *and men* can provide valuable information about how best to support these decision-making processes