Managing screening technologies under uncertainty

Results from a Population Survey and Citizen Deliberations about Mammography Screening in Ontario

Julia Abelson, PhD

Co-authors: L. Tripp, M. Brouwers, J. Sussman
McMaster University

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Background

- net benefits of organized mammography screening (for average-risk women) increasingly questioned as larger body of evidence accumulates

- mammography screening by itself has not had the impact on reducing mortality that we’d hoped it would

- harms associated with screening of concern
  - especially overdiagnosis and overtreatment (but lack of agreement about magnitude of the problem)
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
  - **3** Treated but die

Source: Breast Cancer Now (UK charity)
Challenges for policy makers

- 40+ years of promoting and building up organized mammography screening
- Institutionalized screening programs in most provinces and territories
- Well-recognized program among general public
- Current evidence challenges prevailing attitudes ("early detection is a good thing")
Informed choice as a policy response?

- recent work in Australia & the UK
- little known about Canadian women’s knowledge, values and attitudes in this area
- challenges with varied information sources and conflicts of interest
  - organized screening programs (informing and recruiting)
  - primary care providers (informing and incentivized to screen through pay-for-performance bonuses)
Methods

- Four *citizen deliberations* with (mostly) screen-eligible women (n=49)
  - recruitment aims: geographic diversity (northern, large urban, small rural cities); high and low screening rate communities; 1 provincial event
  - multiple recruitment methods: previous deliberations, community newspaper ads & kijiji, Asking Canadians panel (survey respondents)

- *Population survey* of 2,000 screen-eligible women across Ontario
  - online survey (AskingCanadians panel); recruited through major loyalty programs
  - 2,549 expressed initial interest; 186 non-completers; 363 excluded due to ineligibility (breast cancer diagnosis, health care professional, employed by a cancer screening organization or cancer charity)
Deliberation details

• 1.5 day deliberations (evening presentation and discussion of evidence followed by day-long deliberation)
• pre-circulated reading material and discussion questions
• “Making sense of the evidence” presentation followed by Q & A
• structured, facilitated deliberation in large and small groups with the goal of reaching common ground (but not formal recommendations)
Survey details

- 35 Likert-scaled and categorical questions (informed by a review of other surveys in the field)
  - screening practices; knowledge of breast cancer screening benefits and risks
  - attitudes and values towards screening (perceptions of cancer risk, confidence in knowledge in relation to decision making)
  - desired approaches to supporting informed decision making

- average survey completion time: 13 minutes
- analysis: descriptive statistics, dichotomized variables
- emphasis on comparison between screened vs. never screened (chi-squared tests) informed by previous studies
RESULTS (combined)
Participant characteristics

- average age of survey respondents: 61.6 yrs
- 58% had completed college/university education or higher
- 27% had household income > $80,000
- 70% had close family member or friend diagnosed with breast cancer
- Had at least one mammogram
  - survey respondents (94.6%)
  - deliberation participants (88.6%)
The challenge of long-held beliefs and social norms

- screening is “automatic”

  “It was an automatic I received [the OBSP letter], okay I received this, this is what I’m doing”

  “You just automatically went. Everybody went. Your peers all went.”

- going for a mammogram is the “responsible” thing to do
  — irresponsible for a 55-year old to not have a mammogram (63.3%)

- evidence presented challenges long-held beliefs (difficult for many to come to terms with)

  “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.”
The challenge of fear

- Cancer and breast cancer are feared by many
  - Worried about breast cancer: Some or all of the time (49%)
  - “cancer is something that seems to be the big scary monster”

- Mammography viewed as a way to reduce that fear →
  “you’re doing something to protect your health”
  - Mammography can reduce anxiety about breast cancer: 77% agree
  - You will live longer if you go for regular screening: 51% agree
  - “It seems like we’re doing nothing if we don’t get screened”
The challenges around knowledge...

- knowledgeable about mammography screening (generally) but not for decision making
  - 80% felt informed about mammography
  - 80% also felt not very or not at all informed when making a decision

- pride in being knowledgeable met with surprise and shock when presented with evidence countering beliefs

“The fact that we have all very engaged, informed women here saying that they were presented with information that has never been on their radar before, in spite of the fact that I can’t think of any cancer that has been more talked about, more politicized. I mean how has this not come up before? What else don’t we know?”
The challenge of a lack of balanced information

- screening program materials, websites more likely to emphasize the benefits of screening over the risks
- primary care providers also emphasize benefits over risks
  - more likely to discuss benefits (91.4%) than the risks (43.6%)

“My first reaction to all of the information...was betrayal that my family doctor did not bring any of this up to me...to me that would be a number one discussion that should be had...they should be informing you about that. How can they be telling me that yes, you go and do your mammogram...without ever once mentioning that all of these things could happen...it was just mindboggling.”
How do we address these challenges to support informed decision making?
Access to accurate, complete information even when uncertain

Information needs to be:

- balanced: present both the risks and the benefits
- accurate: do not exaggerate the benefits
- consistent: information women receive should be the same across the country

“When I go to a McDonalds or Tims, I want my coffee to be the same across Canada. So I when I go for a medical treatment...I want to be able to get the same information if I live in Ontario or my child goes to the east coast for school and stays there, I want to know she’s getting the same care as I am.”
Primary care providers play a key role

- trusted source of information
- when women are faced with new information, they want to discuss it with their care providers, esp. when the decision isn’t clear cut

“... 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.”

- transparency is critical

“I can’t make a choice if I’m not well informed. If the information is censored, or I feel like the information is selective, then I don’t feel like I’m empowered to make an appropriate choice”
Final reflections

- continued vigilance to minimize the gap between evidence and balanced discussions

- more attention to integrated decision supports between provincial screening programs and provider community

- sensitivity to the interplay between psychosocial factors, interpretation of evidence, and screening decisions
  - implications for population-level and individually-tailored communication strategies

- more emphasis on incentivizing informed decision making rather than screening?
The challenges of managing uncertainty will continue...

“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”
THANK YOU

Contact details:
Julia Abelson, PhD
Professor, Department of Health Research Methods, Evidence & Impact (HEI)
McMaster University
abelsonj@mcmaster.ca