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4 **Title:** Supporting average-risk women to make informed decisions about mammography when
5 there is no ‘right’ answer: a deliberative study
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29 contributed substantially to the acquisition, analysis and interpretation of data; drafted the article
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31 be published and agree to act as guarantor of the work.
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ABSTRACT

BACKGROUND: Women are encouraged to make informed choices about mammography screening that align with their values and preferences, yet information materials developed by screening programs rarely provide complete, balanced information about screening. Through a series of deliberations with Ontario citizens, we elicited perspectives on materials developed by screening programs to support informed decision-making.

METHODS: Four deliberative engagement events were held with citizens to discuss the current evidence about mammography and informed decision-making in the context of organized screening programs. During these events, participants reviewed and provided feedback on the education materials currently produced by Canadian screening programs and identified the key features that should guide the design of these materials to optimally support informed decision making.

RESULTS: Patient education materials produced by Canadian screening programs were largely viewed as insufficient to support informed decision-making. Participants identified the following key features of optimal education materials: they should be accessible, complete and accurate, and provide information on both benefits and risks of screening in a comprehensive, easy to understand manner. Information materials should evoke the trust of the reader, and they should be consistent across the country.

INTERPRETATION: There is an unmet need for accessible, reliable and balanced sources of information on the evidence about mammography screening. Without access to reliable information sources and complete evidence about screening, women are unable to make fully informed decisions. Canadian breast screening programs must take steps to improve the information they share with women to support informed decision making based on their values and preferences.

INTRODUCTION

In 2018, the Canadian Task Force on Preventive Health Care released updated recommendations on mammography screening for women who are not at increased risk for breast cancer. They continue to recommend women aged 50 -74 years be screened every 2 – 3 years, and women aged 40 – 49 not be screened.(1) The recommendations, however, are now “*conditional on the relative value that a woman places on the possible benefits and harms from screening*”, suggesting there is no ‘right’ decision when it comes to screening and women should make decisions that fit with their values and preferences.(1)

To make informed decisions about mammography that align with their values and preferences, women need sufficient information about risks and benefits, and what alternatives to screening exist.(2) Educational materials are one way to share this information with women.(3) Reviews of materials developed by Canadian and international screening programs demonstrate that most include little information about the risks and overall are biased towards screening.(4-9) A recent survey of Ontarians found that women report confidence in their knowledge about screening but do not feel like they are making informed decisions.(10) To support decision-making, some jurisdictions are updating materials to put women’s needs at the forefront,(11, 12) but little has been done in Canada to explore this issue. In this paper, we explore the types of information that women want to have when making decisions about mammography screening with the goal of supporting screening programs and others involved in developing educational materials.

METHODS

We held four citizen deliberations to elicit citizens' values about mammography screening, with a specific focus on how to support informed decision-making within the context of an organized screening program. Citizen deliberations provide opportunities for citizens to participate in informed discussions about potentially difficult topics which require individuals to make value-based judgements, trade-offs and decisions.(13) Deliberative methods have been used for various health topics in Canada and internationally, including cancer screening.(14) Both JA and LT attended all deliberations; JA facilitated large and small-group discussions, LT facilitated small-group discussions. Both have a personal interest in mammography screening – JA and LT are both female, and both have a family history of breast cancer. Family history was not disclosed to participants. At the time of the deliberations, JA had recently become eligible for screening through the Ontario Breast Screening Program (OBSP) and as a result, was also making screening decisions. This was disclosed to participants during the deliberations.

Participant recruitment and study setting

The study was set in Ontario, a Canadian province which has had an organized breast screening program (OBSP) in place since 1990.(15) The initial deliberation (A) included men and women from across Ontario. To ensure geographic representation, we recruited at least one individual from each of Ontario's Local Health Integration Networks (LHINs). Men and women were included in this deliberation to allow for a broad set of perspectives to be captured at the outset of the study. Screen-eligible women (50 – 74 with no personal history of breast cancer) were recruited locally for the subsequent deliberations held in three different Ontario communities (B, C, D). Communities were selected to allow for geographic diversity (northern, rural, urban) and

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3 mammography screening uptake (high, average and low). A variety of recruitment strategies
4 (both direct and indirect) were used across the deliberations to allow for comparisons by
5 recruitment mode (results to be presented in a separate paper; Table 1). Potential participants
6 completed a short survey to confirm eligibility; those employed in a cancer screening
7 organization were excluded. The study was reviewed and approved by the Hamilton Integrated
8 Research Ethics Board (# 15-008). All participants consented to participate, received \$75 for
9 their participation, and were reimbursed for travel expenses.
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21 ***Data Collection***

22 Each deliberation lasted 0.5 – 1.5 days and consisted of information sharing before and during
23 deliberations and large and small group discussions. Prior to their deliberations, participants were
24 mailed a summary of the current evidence on mammography screening (drawing on published
25 reviews) and the deliberation topic. Participants also viewed presentations given by an oncologist
26 and family physician outlining the history of mammography, the current state of evidence and
27 how evidence informs practice. Deliberation A participants viewed the presentations live (in
28 person, or via webcast); others viewed a recording. One expert was available at the outset of all
29 deliberative events to answer participants' questions. Additional information was also shared by
30 the facilitator during deliberations.
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47 Participants engaged in discussions led by experienced facilitators using a facilitation guide. The
48 questions guiding the deliberations were: i) what can citizen and patient values should be
49 reflected in breast cancer screening programs, and ii) what principles should guide the
50 development of materials to support informed decision making about breast cancer screening?
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3 This paper focuses on the second question which was addressed primarily through a small group
4 activity where participants were asked to review pamphlets developed by provincial/territorial
5 screening programs. Participants provided feedback on these materials and reflected on how they
6 could support informed decision making. Each provincial and territorial screening program's
7 website was reviewed to identify English-language materials that were readily available to the
8 public for this activity. When materials were not accessible online, we emailed the screening
9 program to request the material. Pamphlets were collected from 10 / 12 screening programs.
10 Materials were not available from Prince Edward Island and New Brunswick. Each of the
11 collected pamphlets was reviewed by at least 2 deliberation groups; all groups reviewed the
12 OBSP pamphlet and invitation letter.
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29 *Data Analysis*

30 Deliberations were audio recorded and transcribed verbatim. NVivo 12 was used to manage the
31 data analysis. Transcripts were analyzed using content analysis, guided by the principles of
32 qualitative description and constant comparison. The coding scheme was developed iteratively
33 and refined as data were reviewed and new themes identified, confirmed or rejected through
34 constant comparison both within and across transcripts. The authors discussed the coding
35 throughout to ensure reliability.
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47 **RESULTS**

48 *Participants*

49 Forty-nine individuals participated across four deliberations. Detailed participant characteristics
50 are included in Table 2. Deliberation A included five men; all other participants were female.
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3 Five of the female participants (11.4%) had never had a mammogram. Over one-third (38.8%,
4 n=12) of participants reported a close family member had been diagnosed with breast cancer.
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10 ***Program materials: Core principles***

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12 Through discussions and reviews of existing program materials from across Canada, participants
13 highlighted a series of core principles (explored below) that should guide the development of
14 future screening materials. Illustrative quotes for each are provided in Table 3.
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21 *Accurate, evidence-based*

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23 Participants felt strongly that materials shared with the public by screening programs must be, at
24 their core, evidence-based and accurate. There was a clear desire for materials to include the
25 most up-to-date evidence available. Some raised questions about the evidence in existing
26 program materials – in many cases participants felt that materials were incomplete, lacked
27 sufficient information about the risks of screening or placed inaccurate emphasis on screening
28 benefits. Participants acknowledged that evidence about mammography screening may be
29 uncertain and encouraged screening programs to acknowledge this uncertainty. Materials that did
30 not portray mammography as a ‘perfect’ test were highlighted by participants as a positive way
31 to address uncertainty.
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47 Accuracy was not only important for supporting informed decision-making, but also critical for
48 maintaining trust. Participants wanted to trust that organizations were providing the most
49 accurate and up-to-date evidence and felt when they used leading language or presented
50 imbalanced information, this trust was eroded.
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6 *Comprehensive*

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8 Participants were clear that information shared by screening programs should be comprehensive.

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10 While many participants suggested women connect with a health care provider before making a
11 decision, they acknowledged this would not always be possible and felt that materials should
12 include all information needed to make a decision. Although participants understood and
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While many participants suggested women connect with a health care provider before making a decision, they acknowledged this would not always be possible and felt that materials should include all information needed to make a decision. Although participants understood and acknowledged the variability in the amount of information women need to feel informed, given these are population-based programs where materials cannot be individually tailored, they felt it best to include as much information as possible. Structuring and presenting information so readers can easily and quickly identify information of interest was identified as a way of mitigating this issue. Examples include adding a table of contents to the beginning of the pamphlet; presenting information in different ways (e.g., tables, graphs, infographics); and, using a question and answer format or strong headings so relevant information can be easily identified.

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36 *Choice*

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Participants value materials that clearly emphasize mammography screening as a choice, rather than an expectation. Many participants' felt some pamphlets gave the impression that programs assumed and expected that women would be screened. Participants wanted information materials to be "*neutral, don't sell me on the mammography, give me the information so I can make a choice*". (A) Participants felt information needed to be "*geared towards empowering people through information, enabling them to make the right decision*". The tagline of the Quebec brochure, "*It's your decision*", was identified by many as a good example of this.

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3 Participants were especially clear that content should not assume a decision has already been
4 made by talking exclusively about what will happen during a screening appointment. Though
5 this information is important for women who choose to be screened, they were clear that the bulk
6 of the materials should focus on providing evidence and support to help women make that
7 decision. Information should also be included for those who choose not to screen.
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17 *Accessible*

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19 Participants spoke to the importance of information being accessible. They indicated that
20 materials should be accessible to women of screening age, both in terms of presentation and
21 formatting (e.g., the font size must be appropriate so materials can be read), and in how the
22 information is written. Second, information must be accessible to women in terms of its
23 availability. Women should have easy access to information on screening. Pamphlets should be
24 shared with women in a multitude of ways (e.g., sent directly to women by programs, and
25 through other means such as health card renewal letters); information should be available in
26 public places where women congregate (e.g., spas, recreation centres, libraries); and, information
27 should be shared with women prior to age 50 so the women themselves understand that they will
28 have a choice to make and will be prepared to make this decision.
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44 *Consistent*

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46 All materials reviewed were from Canadian screening programs, yet little consistency was seen
47 across the materials in regard to messaging, framing of the evidence, and the amount of
48 information provided. Participants were concerned about the lack of consistency given that most
49 women will only ever see the material from their local program. As a result, they wouldn't know
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3 there is variability in the information shared across the country and may not be aware the
4 information is incomplete. For some, this was an equity consideration – all women in Canada
5 should have access to the same high-quality information, regardless of where they live.
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7 Participants suggested that consideration should be given to developing a single program
8 material that could be used across Canada and tailored as needed to include “*tailored*
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15 *information...[about] how to access mammograms, where to call*” (D).
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19 *Transparent*

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21 Although provincial screening programs are the primary source of information materials
22 received by women and thus play a key role in informed decision-making, a number of
23 participants were skeptical that programs could provide balanced, unbiased information about
24 mammography screening. The very nature of the program – one that was focused on screening
25 individuals for cancer – was perceived as creating bias given it’s in programs’ best interest to
26 encourage screening and thus “*it’s not in their best interest*” (A) to provide information on
27 potential harms.
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40 While acknowledging these potential conflicts, participants expected screening programs to
41 address them. They spoke of screening programs as credible organizations, that “*the onus should*
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45 *be on them to be more balanced*” (A) and suggested that if this information is not presented “*it*
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49 *hurts the credibility of the organization*” (A). Regardless of who provides the information,
50 participants felt they needed to know that materials were comprehensive and that organizations
51 were being transparent about their biases, and about the screening information available. In
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3 practice, this would mean providing detailed information, including risks, not just the
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5 information that demonstrates screening in a positive light.
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10 *Formatting considerations*

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12 Participants also provided feedback on the look and feel of the program materials (Table 4). Key
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14 considerations included ensuring that images were generic, relevant to their target audience and
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16 did not overpower the information. They wanted information provided in way that was
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18 manageable to review and that captured the reader's attention and provided in a multitude of
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20 ways to accommodate different learning styles.
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26 **INTERPRETATION**

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28 Deliberation participants felt strongly that educational material need to support women in their
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30 screening decisions. While for many, mammography had always been something that they
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32 assumed was the 'right' thing to do, upon learning more about the evidence it became clear that
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34 there was a choice to be made. Participants in this study confirmed previous work that suggested
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36 that screening program materials were largely insufficient to support decision making.(7-9)
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40 Participants were largely unaware of the evidence prior to attending the deliberation sessions,
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42 and on the whole, did not find the program materials provided enough information to support
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44 informed decision-making. Screening programs should consider how educational material can
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46 continue to be revised drawing on the core principles identified through these deliberations.
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52 At a time when the responsibility for making decisions about mammography screening is being
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54 placed firmly into the hands of women, and when it becomes more commonplace to
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3 acknowledge that there is no ‘right’ choice when it comes to screening, it is imperative that good
4 quality, accurate and balanced educational materials are available to all Canadian women.
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7 Despite the challenges that come with taking a pan-Canadian approach, given individual
8 provincial screening mandates, our study participants were clear in their desire for consistency in
9 the types of materials provided to women across Canada to ensure equitable access to screening
10 information and evidence.
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19 This study is the first comprehensive analysis of population-based perspectives on how to
20 support informed decision making about mammography screening that we are aware of in
21 Ontario, and the first in-depth analysis of Canadian mammography screening educational
22 materials from the perspective of the public. This study is not without limitations. Participants
23 who volunteered to participate may have had a stronger interest in mammography screening, and
24 thus their perspectives may be different from those in the broader population. Study participants
25 were more likely to have completed at least some post-secondary education (81.6% compared to
26 45%) and more likely to have a family income of more than \$60,000 (57.1% compared to
27 32.1%) than the general Ontario population (16), again potentially limiting their comparability.
28
29 The study included Ontarians only, and thus may not reflect the views of Canadian women of
30 screening age in other regions although we have no basis to believe that geographic region would
31 influence perspectives on informed consent and program materials. Additional work should be
32 completed with women from other regions in Canada to address this gap, especially given the
33 desire for pan-Canadian approaches to information sharing. Further research in this area is also
34 needed to understand how women can be supported to make informed decisions, including how
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3 screening program materials should be shared with women, when, and what additional supports,
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5 if any, are needed.
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10 The Canadian Task Force on Preventive Health Care has called on health care providers,
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12 screening programs and others to help women consider their values and preferences to make
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14 informed decisions about screening. An important first step in this process is to ensure that the
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16 information available to women who are making decisions is current, complete and consistent so
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18 that it support fully informed screening decisions and emphasizes that screening is a choice
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20 women can make.
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TABLE 1. CHARACTERISTICS OF THE CITIZEN DELIBERATIONS

Panel	size (n) ^a	Geographic Location	Population (2016)(17)	OBSP Screening Rate ^b	Recruitment Strategies Used			
					Previous Panel	Print Ad	Online Ad	Online survey panel
A	13	Ontario	13,488,494	43.2%	X			X
B	12	Northern Ontario	107,909	48.7%		X	X	
C	12	Southern Ontario	97,496	59.3%		X	X	
D	12	Greater Toronto Area	2,731,571	34.9%				X

^a 7 individuals withdrew from the study prior to the event due to unanticipated scheduling conflicts.

^b Age standardized percentage of screen-eligible average-risk women, ages 50–74, who completed at least 1 mammogram with the Ontario Breast Screening Program (OBSP) within 2010-11 (18)

TABLE 2. PARTICIPANT CHARACTERISTICS, CITIZEN DELIBERATIONS

CHARACTERISTIC	DELIBERATION				TOTAL* n (%)
	A N=13	B N=12	C N=12	D N=12	
Demographic Characteristics					
<i>Age</i>					
39 or under	1	0	0	0	1 (2.0%)
40 – 49	1	0	0	0	1 (2.0%)
50 – 59	5	9	8	7	29 (59.2%)
60 – 69	4	3	4	4	15 (30.6%)
70 and older	2	0	0	1	3 (6.1%)
<i>Highest level of education completed</i>					
No schooling	0	1	0	0	1 (2.0%)
Elementary school	0	1	0	0	1 (2.0%)
High school	2	2	2	0	6 (12.2%)
Completed some post-secondary	0	0	0	4	4 (8.2%)
College	3	2	6	2	13 (26.5%)
Bachelor's degree	3	5	3	5	16 (32.7%)
Post-graduate training or professional degree	4	1	1	1	7 (14.3%)
No response	1	0	0	0	1 (2.0%)
<i>Income</i>					
Less than \$20,000	1	1	1	0	3 (6.1%)
\$20,000 - \$39,999	0	2	1	1	4 (8.2%)
\$40,000 - \$59,999	0	1	2	2	5 (10.2%)
\$60,000 - \$79,999	2	3	5	1	11 (22.4%)
\$80,000 - \$99,999	1	1	0	3	5 (10.2%)
\$100,000 or more	7	0	2	3	12 (24.5%)
Prefer not to answer	2	4	1	2	9 (18.4%)
Experience with cancer					
Personally diagnosed with a cancer other than breast cancer	2	1	1	2	6 (12%)
Close family members had been diagnosed with breast cancer	2	4	8	5	19 (39%)
Experience with mammography (females only, n=44)					
Never had a mammogram	0	2	1	2	5 (11.4%)

TABLE 3 PRINCIPLES TO SUPPORT THE DEVELOPMENT OF PROGRAM MATERIALS AND ILLUSTRATIVE QUOTES

KEY PRINCIPLE	ILLUSTRATIVE QUOTES
Accurate, evidence-based	“Okay. The best way you protect your health is by getting a mammogram every 2 years. The best way to protect my health? Well there’s lots of ways to protect my health and they have nothing to do with getting mammograms. So that may be a big statement to make, it’s not entirely true.” (Panel B)
Comprehensive	<p>“I have to read this and think this is what I want to do. Not hmm, maybe I need to research more. It should give me everything I need as a good starting point to make a decision” (Panel B)</p> <p>“You see here, and they are all guilty of the same darn thing – are mammograms safe? Do they hurt? All they do is talk to the actual mammogram...not about risk, ever, really, anywhere.” (Panel A)</p> <p>“It’s almost like it needs an index at the front that has the categories of information that are in there. So if all you’re looking for is how should I prepare for my appointment, you go to page 5. If it’s what should I be expecting from my doctor, it’s a little bit of a table of contents almost that would guide you through it. Because I think there’s a lot of good information in here but I agree with you, anybody who would actually sit down and read through the whole thing is probably fairly minimal. But it’s like well, there’s the one thing that I’m wondering about that I would like to find.” (Panel D)</p>
Choice	<p>“Just enough [information] to make that informed decision and choice, that’s what I value. Informed choice. Educated decisions.” (Panel B)</p> <p>“I think the only other thing...[is] sort of asking the question when you get the letter of how to decide if breast cancer screening is right for you. So it’s some considerations like even a hint at there are some things that you should think about. How to decide if it’s right for you. And maybe it’s 4 or 5 provocative questions that you should be asking yourself.” (Panel D)</p>
Accessible	“The font is clearly not for the 50 – 74 age group and I find that so annoying because look at who is trying to read this. And we hate getting our reading glasses out.” (Panel C)
Consistent	“When I go to a McDonald’s or Tim’s, I want my coffee to be the same right across Canada. So when I go for medical treatment – and that’s more important to me than my coffee – I want to be able to get the same information if I live in Ontario or [if] my child goes to the

	<p>east coast for school and stays there, I want to know that she's getting the same [information] as I am" (Panel C)</p> <p>"This should be a national discussion, it doesn't really matter where we live, we're all going to be affected the same way" (Panel D)</p>
Transparent	<p>"This idea of treating as many people as possible – that's totally in conflict with the idea of supporting people in making a choice and a decision, because the [earlier] part is saying that we're going to keep pushing people, regardless...our goal is to get as many people as possible through screening, if they decide it's appropriate for them or not" (Panel D).</p> <p>"This one that does the risks and the benefits is nice because I think I tend to believe more. If they give you the benefits and they give you the risks too, it's almost giving it more credibility [Alberta] because they are telling you what the risks or the cons are as well. So to me this gives this more credibility." (Panel B)</p>

TABLE 4. PRACTICAL SUGGESTIONS FOR IMPROVING INFORMATION MATERIALS

AREA OF FOCUS	FEEDBACK
Formatting	<ul style="list-style-type: none"> • Use of bold or highlighting (colour) to attract the reader's eye is helpful for key points • Font size must be large enough to be easily read; consider your primary audience (e.g., women over 50 years of age) when determining the formatting of the materials • Use colour to catch the reader's eye – something needs to draw them in, so the materials don't seem too technical or 'dull' • Do not provide too much information on one page. If including information on both sides of a page (e.g., a letter) be certain that the reader knows to turn the page over • Cover needs to grab the attention of the reader
Statistics	<ul style="list-style-type: none"> • Present statistics for all issues, even if there is uncertainty in the data (e.g., for overdiagnosis) • Provide comparisons (e.g., mortality rates for screened and unscreened women) to put information into context • Present the information in different ways to ensure understanding (e.g., numbers, charts, graphs, info-graphics) • Present the statistics as # in 100 or # in 1000 as those are the easiest numbers to relate to
Images	<ul style="list-style-type: none"> • Use images sparingly • Images can be used to get key information across (e.g., photos of a mammography machine) • Avoid photos of people, where possible, so all citizens can see themselves in the photos • When including photos of individuals, ensure the diversity of the population is captured and that the photos represent the target audience (women, 50 – 74 years)
Structure of information	<ul style="list-style-type: none"> • Use headings, table of contents to make information easy to find • Consider a questions and answer approach throughout the materials, or a FAQ section • Providing information in a series of short points (bullet-form) can help the reader get through a large amount of information
Language	<ul style="list-style-type: none"> • Consider carefully what language to use when describing risks and benefits: e.g., pros and cons, harms and benefits • Ensure the language supports choice • Be aware of the reading level of the text
Source	<ul style="list-style-type: none"> • Consider other sources of information: social media, websites, e-mail campaign, in-person campaigns television in addition to print materials • Trusted media personalities for the age group could also be engaged to share this evidence (e.g., daytime talk shows)