

Appendix 2 (as supplied by the authors): Facilitation guides

FACILITATION GUIDE: INFORMATION NIGHT - BREAST CANCER SCREENING

ARRIVAL 6:00 – 6:05pm	
Activity	Details
Welcome	Participants arrive for the meeting & registration
WELCOME AND INTRODUCTION 6:05 – 6:25	
Activity	Details
Welcome panel members	Thank everyone for coming Introduce the research team
Agenda	Overview of the evening Quick overview of Saturday – tonight the focus is on learning about the evidence, Saturday’s focus is on discussion
Citizen Panels	Provide a brief overview of what citizen panels are
Why study breast cancer screening?	Provide a brief overview of what’s happening in the research world and society to make this an interesting area to study
Overall study	Describe the broader study Acknowledge funders
Consent	Explain the purpose of consent Review consent form contents Check for questions/concerns ***TURN ON AUDIO RECORDERS ONCE CONSENT FORMS HAVE BEEN SIGNED ***

Ice Breaking Activity	TASK: Introduce yourself and share with us how you heard about this research project and why you decided to respond to the invitation to participate
6:20– 6:45 DINNER BREAK	
The science of breast cancer screening: Introduction to the Evidence 6:45 – 7:00 pm	
Sources of evidence to inform meeting discussions	Highlight the information package that everyone received and the supplementary resources <ul style="list-style-type: none"> - Confirm all received the written materials and read the background info. For those who haven't read it yet, encourage them to read it before Saturday <p>We will be watching the public talk together tonight.</p>
Discussion on evidence	Before the talk, short discussion to get a sense of participants' knowledge about mammography screening... <ul style="list-style-type: none"> • Do you feel like you're well informed about mammography screening? Why or why not? <p>Where do you get your information about mammography screening?</p>
Public Talk	Background on the Public Talk: <ul style="list-style-type: none"> - Held in March as part of the McMaster Health Forum Public Talk series - Introduce the speakers <p>First speaker will join us after the talk to answer questions (write your questions down during the talk)</p>
SHOW PUBLIC TALK 7 – 8:10pm	
Discussion after public talk	Debrief about the talk... <ul style="list-style-type: none"> -What are your initial thoughts about the information that was presented during the public talk? - What surprised you? What felt familiar?
Q&A with Content Expert (public talk speaker) 8:10 – 8:50pm	
Q + A	Questions from the group...
Wrap-up	Reminders for next day... <ul style="list-style-type: none"> - Review meeting material package

	<ul style="list-style-type: none">- Reflect on tonight's information and discussions. What questions do you still have? What surprised you?
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FACILITATION GUIDE: CITIZENS' PANEL ON BREAST CANCER SCREENING

ARRIVAL 9:00 – 9:15 am	
Activity	Details
Participants arrive for the day	Light breakfast will be served (pastries, tea, coffee)
Welcome panel members	<p>Thank everyone for coming back</p> <p>Remind them that the day will be audio recorded. If no one has an issue with this, turn on the recording devices.</p> <p>Introduce new members of the research team</p>
Agenda	Provide an overview of the agenda for the day
Research questions	Review of the research questions to be addressed in this session
Ground rules for discussion	<p>Ground rules for the day's discussion</p> <ul style="list-style-type: none"> • 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	<p>Take time to get to know each other again...</p> <p>Now that you've had time to reflect on everything you heard on Thursday night about mammography screening, tell us the following:</p> <ul style="list-style-type: none"> - What did you think was the most important piece of information shared? - What was the most difficult idea to understand? <p>What have you thought about the most since then?</p>

REFLECTING ON THE EVIDENCE

9:30 – 10:00 am

Activity	Details
Overview	Will go over some of the important evidence, highlighting some of the points that didn't come up on Thursday night or that you said you'd want to hear more about
Breast cancer in Canada	Some statistics about breast cancer in Canada <ul style="list-style-type: none"> - 1 in 9 women will be diagnosed with breast cancer - 1 in 30 will die of breast cancer - majority of breast cancer cases are diagnosed in women over the age of 50.
Average vs high risk women	Our conversations are focused on average risk women. The vast majority of women in Ontario are of average risk. OBSP defines high risk as women who: <ul style="list-style-type: none"> - Have the BRCA1 or BRCA2 gene putting them at higher risk – or their family members have it but they themselves have declined genetic testing - Had chest radiation for another cancer prior to age 30 - Have a very strong family history (multiple first and second-degree relatives, cases that are very aggressive (both breasts), early or combined with ovarian cancer)
Breast cancer screening in Ontario	The Ontario Breast Screening Program is a program of Cancer Care Ontario. They offer screening to all eligible women in Ontario – a Population-based screening approach. Women are eligible to participate in the average-risk screening program if: <ul style="list-style-type: none"> - they are 50 – 74 years of age - they do not have any symptoms of breast cancer (no lumps, etc.) - do not have breast implants (these women can still be screened, but not through the OBSP) - and they have never been diagnosed with breast cancer If women aren't eligible for the OBSP, they can access screening outside of the program with a referral from their physician. No referral is needed for the OBSP
Screening Process	This slide gives a sense of the screening process...

	<p>The OBSP sends women who are turning 50 or who have not been for a screening in a number of years an invitation to be screened.</p> <p>Some women will decide not to be screened.</p> <p>If a woman wants to go for screening she can call her local OBSP site to book an appointment. She then goes for her mammogram. If the results are normal she will receive a letter saying this and her doctor will be informed. She will then receive a recall letter in 1 – 2 years from the OBSP reminding her to come back. Most women will be recalled every 2 years. Some women may be recalled annually due to family history or because their breast tissue is very dense.</p> <p>If the mammogram is abnormal, her doctor will be informed and her doctor or the OBSP will contact her to schedule follow-up testing. This could include another mammogram, ultrasounds or a biopsy. If the results come back normal this is termed a false positive. The woman will re-enter the OBSP cycle, and will be recalled for her next screening in 1 – 2 years as normal.</p> <p>If the results show breast cancer, the woman will then meet with an oncologist to determine the next steps.</p>
Screening rates	<p>The OBSP and other screening programs across the country aim to screen at least 70% of all eligible women. This means that 70% of average risk women between the ages of 50 – 74 would have been screened within the last 24 months.</p> <p>Currently Ontario is screening 59% of the population – this includes both OBSP and non-OBSP screenings.</p>
Risks and benefits of screening	<p>We discussed the risks and benefits of screening in a fair amount of detail on Thursday night. As a reminder...</p> <p>The benefits of screening include the fact that some lives will be saved. It's estimated that for every 720 women that are screened (in their 50s) one life will be saved. Also in some cases the type of treatment needed might change – if cancers are caught earlier, less intensive treatment may be needed.</p> <p>There are real risks to screening, too. False positives, false negatives, unnecessary biopsies and overdiagnosis.</p> <p>Ask the group to define each of the risks, give examples.</p> <p>See pages 9 and 10 in workbooks</p>

	<p>These charts highlight the difference between 1,000 women who are screened for breast cancer with mammography, and 1,000 women who are not.</p> <p>Set up for next slide: different studies report different estimates for these categories, esp. the overdiagnosis category... next slide emphasizes this.</p>
	<p>A challenge with the evidence on breast cancer screening is the fact that there are variations in the estimates of the magnitude of the benefits and risks</p> <p>Recently Dr. Alexandra Barratt from Australia published an article on this issue, specifically focused on overdiagnosis.</p> <p>Task: Audio clip – play from 10:16 – 12:22 of the interview</p>
	<p>Ethical and Social Values</p> <p>10:00 – 10:45am</p>
Activity	Details
What do we mean by societal values?	<p>Broadly shared values in society which bear on the appropriate use and impact of the technology</p> <p>Examples: access, quality, choice, resource use, public expectations</p> <p style="text-align: center;">Each of these may be more or less important to different technologies and their impact on society.</p>
What do we mean by ethical values?	<p>Moral principles or beliefs about how technologies should be used</p> <p>Examples: balancing harms and benefits, respect for human rights and dignity, patient consent, autonomy</p> <p style="text-align: center;">Highlight that sometimes there can be conflicts between values</p>
Values to consider	<p>Here is a list of some values that you may want to consider when you're thinking about these issues... (see slide)</p>
Discussion	<p>Task: Discussion</p> <p>Now that you're in the mindset of thinking about values and have a sense of what social & ethical values are...</p>

	<ul style="list-style-type: none"> • What societal and ethical values should be considered in the design of provincial screening programs? • Get participants to brainstorm about what is important to consider, then from there identify which are the most important ones to consider
Informed Consent 11:00 am – 12:00 pm	
What is informed consent?	<p>Cathy Risdon’s presentation on the video the other night raised a number of issues about her role in supporting patients who are making decisions about breast cancer screening.</p> <p>In the medical and research fields, we often related these activities to something called informed consent</p> <p>Informed consent: making a decision about an activity/action based on the risks and benefits and the individual’s own circumstances and beliefs</p> <p>Situations where you may have to provide informed consent: medical context (tests, procedures); research context (participation in studies – Thursday evening)</p>
Group discussion	<p>Task: Group discussion</p> <p>Discussion questions:</p> <ul style="list-style-type: none"> • As a potential user of a screening test... <ul style="list-style-type: none"> ○ 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? <p>In the context of breast cancer screening, is informed consent important? Why or why not?</p>
Informed consent VIDEO	<p>Video clip was developed by the Canadian Task Force on Preventive Health Care. This was developed as part of their process for sharing the new breast cancer screening guidelines with the public and practitioners.</p> <p>Task: Watch video</p>
Video - Discussion	<p>Task: Brief discussion</p> <p>What were your initial reactions to this video?</p> <p>Put yourself in the shoes of the patient in the video...</p> <ul style="list-style-type: none"> • Did you have sufficient information to make an informed decision?

	<ul style="list-style-type: none"> • Did they provide too much information? Too little? What questions remain? <p>Put yourself in the shoes of the physician now...</p> <ul style="list-style-type: none"> - How would you approach this conversation - What would you do differently <p>Prompts: How could policy level changes support the physician in these situations?</p>
What are decision aids?	<p>Tools can be very helpful to patients and their health care providers as they are making decisions about things like whether to be screened or not.</p> <p>Decision aids are examples of these kinds of tools... [Harding Risk Literacy tool] They 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 by clarifying personal values</p> <p>Designed to compliment counseling from a health practitioner, not replace it</p>
Ideally decision aids, should	<p>Highlight what decision aids should include, according to experts (Ottawa Hospital Research Institute)</p> <ul style="list-style-type: none"> • Describe the condition related to the decision • Include balanced information about the decision to be made • Highlight the options available • 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 <p>NOTE: In the case of mammography screening, the alternative option to screening is to not go for screening – providing information on what are the risks and benefits of both options (i.e., the number of lives saved if you go for screening compared with the number of lives saved if you don't go for screening) would be a valid comparison.</p>
Challenges	<p>Not all decision aids are equal – many do not provide a balanced overview of both the benefits and risks</p> <p>Often they are distributed by screening programs</p>

	<p>Highlight the work done by the Citizens' Jury in the UK</p> <p>Task: Listen to the next portion of Dr. Barratt's interview (starting at 14:33)</p>
Group discussion	<p>Have you ever consulted brochures or other materials when trying to make a decision about screening?</p> <ul style="list-style-type: none"> - What did you consult? - How did you access these information sources? - Did you find them helpful? What information did you wish you had? <p>What principles do you think should guide the development of materials to support informed decision-making?</p>
Content & Style of Decision Aids	<p>There are many different ways to present information about breast cancer screening, and the best ways to do this is something we want to discuss when we break into small groups this afternoon.</p>
Main message	<p>For example, the way the cover looks and the tagline can change the message that comes across....</p> <p>(US advocacy group, Australia, NHS)</p>
Presenting information	<p>There are lots of ways to present information...</p>
New concepts	<p>And different ways to introduce new concepts...</p> <p>All of this will be important to consider when we are working in small groups over lunch.</p>
LUNCH 12 – 12:45pm	<p>If you haven't reviewed the information materials already, please do this over the lunch break.</p>
<p>Introduction to group activity 12:15 – 1:00pm</p>	
Describe group activity	<p>We will be breaking the panel into 2 smaller groups</p> <p>In these groups, we'd like to address these questions:</p> <ul style="list-style-type: none"> • First: In light of the conflicting evidence on mammography screening, informed decision-making is important. At the individual level, what information do you think women need to make this decision? • We are then going to show you different decision aids – both groups will look at the Ontario Breast Screening Program brochure, and each will look at another from 1 -2 other provinces. While you look at these, we'd like you to think about the questions on the power point slide.

	<ul style="list-style-type: none"> Finally, we want you to think about who is the best person/group to be providing this information to women? <p>In each group, please identify someone who will take notes and someone who will act as the “rapporteur” who will report to the larger group about the 3-5 key ideas that emerged during your discussions.</p> <p>We will report back after our break</p>
BREAK 2 – 2:15pm	
Report back 2:15 – 2:45pm	
Group activity – report back	<p>1 person per group to report back on what was discussed. Use questions as a guide to prompt.</p> <p>Slides with the decision aids reviewed by both groups available during report back if needed.</p>
Policies to support informed decision making 2:45 – 3:30	
Screening Programs	<p>Screening programs fill a dual role: provide information to support informed decision making and promote screening to increase screening rates</p> <p>The goal for breast screening programs across Canada is to achieve 70% participation</p>
Discussion	<p>Questions:</p> <ul style="list-style-type: none"> What can be done at a policy level to support informed decision-making? Who should be involved in this work? How should screening programs balance their obligations to <i>provide information and choice</i> to screening program participants, and their interests in <i>screening as many people as possible</i> to reduce cancer deaths across large populations? Can they do both effectively?
Wrap-Up	
Elevator speech	Ask each person to give their 30 sec elevator speech to key decision makers if they had the opportunity to do so...

Thank you and closing

Thank the group for coming and sharing their thoughts
Reminder that we will be mailing or e-mailing a summary of the findings at a later date