

Supplemental Materials for

A Patient Decision Aid for Contralateral Prophylactic Mastectomy for Use in the Consultation: A Feasibility Study

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Listing of Supplemental Material(s):

Supplemental Appendix 1: Patient Decision Aid

Supplemental Appendix 2: Healthcare Provider Online Survey

Supplemental Appendix 3: Patient Survey

Supplementary Appendix 1 - Patient Decision Aid

Should I have my other breast removed when having surgery for early breast cancer?

A Consult Decision Aid for patients and doctors to discuss options

1. Why are we discussing removing the other breast for **early breast cancer**?

- Women with early stage breast cancer are offered surgery to have only the breast cancer removed or their entire breast removed. With both types of surgery, women may also need other treatments such as chemotherapy and/or hormone therapy.
- When the entire breast is removed, the breast can be recreated with reconstruction surgery.
- When women are choosing to have the entire breast removed, they may think about whether or not to have the other (healthy) breast removed. This is called contralateral prophylactic mastectomy. Removal can be completed at the same time as the initial surgery for breast cancer or at a later time.
- Women with a BRCA1 or BRCA2 gene mutation, a strong family history of breast cancer, or who received chest radiation therapy before age 30 have a higher chance of getting breast cancer in the other breast.

2. What are your options?

Surgically remove both breasts

Surgically remove only the breast with breast cancer

3. What do you think of the benefits and risks of each option?

- a) Shown below are the best estimates of what happens to 100 people with **early breast cancer** who have one or both breasts removed. Link to a more [detailed table](#).
- b) Review the table, add other reasons you may have to choose/avoid options and choose stars to show how much each one matters to you.
- c) Other information to consider: your overall health (i.e. other medical conditions, smoking, obesity, etc), anticipated changes to your emotions over time, recovery and possible time off work, complications, and other reasons).

	Have both breasts removed	Have one breast removed	How much does this matter to you? 0★(not at all) 5★(a great deal) 
Benefits or Reasons to Remove Both Breasts			
Fewer women get breast cancer in the other breast	<1 out of 100 get cancer in other breast over 10 years	2-6 out of 100 get cancer in other breast over 10 years	★★★★★
No need for routine mammograms after surgery	✓	--	★★★★★
An option to look more the same on both sides	✓	--	★★★★★
For women who have reconstruction, more satisfaction with new breasts	✓	--	★★★★★
Add other reasons to have both breasts removed			★★★★★
Risks or Reasons to Avoid Removing both Breasts			
Twice as many complications from surgery [i.e. bleeding, wound infections, additional surgeries]	8-14 out of 100 have a complication within 1 year	4 out of 100 have a complication within 1 year	★★★★★
Possible delay in scheduling surgery and additional cancer treatments	✓	--	★★★★★
Does not increase chance of cure for your known cancer	✓	✓	★★★★★
For women who have reconstruction, no difference in physical, emotional, and sexual well-being (at 4 years)	✓	✓	★★★★★
Not 100% guarantee of preventing breast cancer on other side	✓	✓	★★★★★
Add other reasons to avoid having both breasts removed			★★★★★

4. Which option do you prefer?

Remove both breasts Remove one breast Unsure

5. What are your decision-making needs?

<p>Sure of myself you?</p> <p>Understand information option?</p> <p>Risk-benefit ratio you?</p> <p>Encouragement choice?</p>	<p>Do you feel sure about the best choice for <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Do you know the benefits and risks of each <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Are you clear about which benefits and risks matter most to <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Do you have enough support and advice to make a <input type="checkbox"/> Yes <input type="checkbox"/> No</p>
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The SURE Test

Hyperlinked additional Information

What does the research show? Blocks of 100 faces show a ‘best estimate’ of what happens to **100 women** who either have both breast removed or have one breast removed. Each face ☺ is one person. The shaded areas show the number of people affected. There is no way of knowing in advance if you will be affected.

	Remove both breasts	Remove one breast
Benefit(s): Less chance of getting breast cancer in the other breast	99 No breast cancer in other breast <1 Get breast cancer in other breast 	96 No breast cancer in other breast 4 Get breast cancer in other breast 
Risk(s): At least twice as many complications after surgery	~92 No complications ~8 Post-operative complications 	96 No complications 4 Post-operative complications 

The SURE Test: ©2008 O’Connor & Légaré: People who answer “No” to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes. It is important to work through the decision step by step. (Légaré et al. 2010, Are you SURE?)

References: Boughey et al. (2016) Contralateral prophylactic mastectomy consensus statement. American Society of Breast Surgeons Part I: data on CPM outcomes and risk; Part II: additional considerations and a framework for shared decision making.

Expert Team: A Roberts, A Arnaout J Squires, D Stacey.

Supplementary Appendix 2 - Healthcare Provider Online Survey

Survey

1. What do you like or not like about the Contralateral Prophylactic Mastectomy (CPM) decision aid?

2. Did you find that the amount of information included in the CPM decision aid was:

- Much less than I wanted
- Little less than I wanted
- About right
- Little more than I wanted
- Much more than I wanted

3. Are the font and icons (check boxes etc.) readable (i.e. font type and size)?

- Yes No

4. Is there enough space for data entry?

- Yes No

5. Do the words in the CPM decision aid make sense?

- Yes No

6. For the next questions, I will like to ask you to rate each section of the CPM decision aid by choosing 'poor', 'fair', 'good', or 'excellent' to show what you think about the clarity of the information presented:

	Poor	Fair	Good	Very Good
1. Why are we discussing removing of the other (healthy) breast?	1	2	3	4
2. What are your options?	1	2	3	4
3. What do you think of the benefits and risks of each option?	1	2	3	4
4. Which option do you prefer?	1	2	3	4
5. What are your decision making needs?	1	2	3	4
6. Additional Information	1	2	3	4
7. Information on funding / authors	1	2	3	4
8. References	1	2	3	4

7. Did you find that the balance of the patient decision aid was:

- Clearly slanted to having both breasts removed
- Slightly slanted to having both breasts removed
- Completely balanced
- Slightly slanted to having only one breast removed
- Clearly slanted to having only one breast removed

8. How easy was it to understand section 3 (What do you think of the benefits and risks of each option)?

9. For the next questions, I will like to ask you to choose how helpful the decision aid would be by rating the following questions on a scale of 1 to 5, with 1 being 'not at all', and (5) being 'a great deal'.

Table with 6 columns: Question, Not at all, A little, Somewhat, Quite a bit, A great deal. Rows include: Help patients recognize that a decision needs to be made, Prepare patients to make a better decision?, Help patients think about the pros and cons of each option?, Help patients think about which pros and cons are most important, Help patients know that the decision depends on what matters most to them, Help patients organize their own thoughts about the decision?, Help patients prepare questions to their doctor?.

10. Is there information that you would like to see added or removed?

- Yes, added; Yes, removed No
If so, please describe.

11. Can you see this CPM decision aid fit into the discussion with your patients?

- Yes, as it is
- Yes, but with some alterations
- No

If alterations please specify:

12. Would you use it and/or tell someone about the decision aid?

- Yes
- No

13. Do you have any further comments on the decision aid?

We would now like to ask you a few questions about yourself.

14. What is your province of employment? (Please specify _____)

15. What type of hospital do you practice?

- Teaching (university affiliated)
- Community
- Other (Please specify _____)

16. What is your specialty

- General Surgery
- Surgical Oncology
- Plastic Surgery
- Other (Please specify _____)

17. How many years have you been in practice? (After residency and/or fellowship) _____

18. Approximately how many breast cancer patients do you see on a yearly basis? _____

19. How many years of experience do you have working with breast cancer? _____

20. What is your age range?

- Under 30
- 30-39
- 40-49
- 50-59
- 60-69
- 70 and older

21. What is your sex:

- Female
- Male

Thank you for taking the time to complete this survey. Your feedback will be used to revise the CPM decision aid.

Supplementary Appendix 3 - Patient Survey

CPM Decision Aid – Patient Survey Questions

Hello. My name is [*name of research assistant*]. I am an RA working with Dr. Angel Arnaout on the CPM Decision Aid Project.

We are conducting a research study to get feedback on a brief patient decision aid.

Did you get a chance to review the consent form?

If yes, do you have any questions? If no, do you want me to review it with you?

I would like to first begin by reviewing the patient decision aid. The decision aid was designed to help patients with breast cancer on one side to decide whether or not they should have the other healthy breast removed – a surgery called Contralateral Prophylactic Mastectomy or CPM.

At the top of the first page, you will see the specific decision to be made using the decision-aid as the title of the tool.

In Step 1, the decision aid provides a description of the decision circumstances. Step 2 briefly describes the treatment options – [The surgical removal of both breasts, or only the breast with cancer]. In Step 3, the decision aid presents both the benefits, risks, and reasons (e.g. for and against) of for the treatment options. As well, you are asked to rate how much the benefits and risks matter to you on a scale of 0 to 5. In Step 4, you are asked which option you prefer. In Step 5, there are 4 questions to assess any remaining decision-making needs.

At the bottom of each page, there are details available concerning the development of the decision aid. For example, this may include when it was last updated, and who funded the development of the decision-aid. Within the decision aid, there are links to extra information such as the detailed table associated with the risks and benefits of both treatment options, and the SURE test that explains how to interpret the scores in Step 5. Page 3 or the last page displays this extra information accessed through the links.

Do you want to take a few minutes to look at the decision aid on your own?

Now that you we have looked at the decision aid, I would like to get your feedback. As we go through these questions, feel free to add any comments or suggestions that you feel is relevant to the question. You may want to follow-along on the copy I sent to you in email.

1. Did you find that the amount of information included in the decision aid was:

- Much less than I wanted
- Little less than I wanted
- About right
- Little more than I wanted
- Much more than I wanted

2. Did you find that the length of the patient decision aid was:

- Much too long
- Little too long
- About right
- Should have been a little longer
- Should have been much longer

3. Are the font and icons (check boxes etc.) readable (i.e. font type and size)?

- Yes No

4. Is there enough space to write in?

- Yes No

5. Do the various terms in the decision aid make sense? Is it easy to understand?

- Yes No

6. For the next questions, I will like to ask you to rate each section of the decision aid by choosing 'poor', 'fair', 'good', or 'excellent' to show what you think about how clearly the information is presented:

What is the decision that needs to be made?	poor	fair	good	excellent
What are the treatment options?	poor	fair	good	excellent
How do you weigh the benefits and harms of each option?	poor	fair	good	excellent
Which option do you prefer?	poor	fair	good	excellent
More information	poor	fair	good	excellent
Disclosures	poor	fair	good	excellent
References	poor	fair	good	excellent

7. Did you find that the balance of the patient decision aid was:

- Clearly slanted to having both breasts removed
- Slightly slanted to having both breasts removed
- Completely balanced
- Slightly slanted to having only one breast removed
- Clearly slanted to having only one breast removed

8. For the next questions, I will like to ask you to choose how helpful the decision aid was by rating the following questions on a scale of 1 to 5, with 1 being 'not at all', (2)'a little', (3)'somewhat', (4)'quite a bit', or (5)'a great deal'.

	Not at all	A little	Somewhat	Quite a bit	A great deal
Help patients recognize that a decision needs to be made	1	2	3	4	5
Prepare patients to make a better decision?	1	2	3	4	5
Help patients think about the pros and cons of each option?	1	2	3	4	5
Help patients think about which pros and cons are most important	1	2	3	4	5
Help patients know that the decision depends on what matters most to them	1	2	3	4	5
Help patients organize their own thoughts about the decision?	1	2	3	4	5
Help patients identify questions they would want to ask their doctor?	1	2	3	4	5

9. Is there any information missing that you would like to see added or removed?

Yes No

If Yes, please describe.

10. Would the decision aid fit into the discussion with your clinicians (e.g. physician, nurse, pharmacist)?

Yes, as it is

Yes, but with some alterations

No

11. Would you use it and/or tell someone about the decision aid?

Yes

No

12. What do you like or not like about the decision aid?

13. Do you have any other comments on the decision aid?

At this point, I would like to ask you a few questions about yourself.

14. What is your age range?

Under 30

40-50

60-70

30-40

50-60

70 and older

15. What is the highest level of education you have completed?

Did not complete high school

High School

Community college

University undergraduate degree

University graduate degree

16. What is your occupation? _____

17. How long ago did you have your cancer surgery?

- Less than 2 years
- 2-5 years
- 6-10 years
- More than 10 years

18. Have you had CPM?

If yes, how long ago?

- Less than 2 years
- 2-5 years
- 6-10 years
- More than 10 years

19. Is there anything else you would like to share with me regarding the decision aid or this interview process?

Thank you for taking the time to go through this interview with me. Your feedback will be used to revise this decision aid.