

Appendix 1. Supplementary material

CPM Patient Needs Assessment Questionnaire

1. At this time, what do you think are the most important surgical decisions people with breast cancer face?
2. Tell me about the discussion you had regarding your surgical options with your healthcare team.
3. Let's focus on one particular decision that is important and difficult for patients to make, the decision for a double mastectomy. How did the discussion regarding the double mastectomy arise?
 - Who initiated it?
 - If the patient initiated it, how did she learn about this option?
 - How did she feel bringing this up with the healthcare team?
 - How did her healthcare team respond?
4. The decision to undergo a double mastectomy when the cancer has been diagnosed in only one breast may be a difficult one. How did you feel when making this decision?

Did you feel:

- Unsure about what to do?
 - Worried what could go wrong?
 - Distressed or upset?
 - Constantly thinking about the decision?
 - Wavering between choices or changing their mind?
 - Delaying the decision?
 - Questioning what is important to them?
 - Physical signs of stress (tense muscles, racing heartbeat, difficulty sleeping)?
5. What things made the decision difficult for you?

Were you:

- Lacking information about options, benefits, risks?
- Lacking information on the chances of benefits and harms?
- Confused from information overload?
- Unclear about what is important to them?
- Feeling unsupported in decision making?
- Feeling pressure from others?
- Lacking motivation or not feeling ready to make a decision?
- Lacking the ability or skill to make a decision?

6. What do you see as the main advantages/benefits and disadvantages/risks of proceeding with a CPM?

- How does having a double mastectomy affect your future cancer risk?
- How does having a double mastectomy affect the risk of surgery? What about the need for future surgery?
- How does having a double mastectomy impact the way things will look overall?

7. Who else was involved in making the decision with you?

Do they usually:

- Make the decision for the patient?
- Share the decision with the patient?
- Provide support or advice for patients to the decision on their own?
- Lack the ability or skill to make a decision?

8. How do you usually go about making such a decision?

- Get information on option?
- Get information on the chances of benefits and risks?
- Consider the personal importance of the benefits and risks?
- Get information on how others go about deciding?
- Get support from others?
- Find ways to handle pressure?

9. What would have helped make this decision?

- Information, trusted, websites, support from family/friends, support from healthcare team?

10. What got in the way of making this decision?

- Were there conflicting opinions from the health care team?
- Did she feel supported by her health care team in making this decision?

11. Is there anything else that would help overcome these barriers to decision making?

12. I will list possible ways to help some people with a decision, which ones do you think might be useful to you?

Counseling from a health practitioner

- IF YES, specify what types

Discussion groups of people facing the same decision

- IF YES, specify what type of organization or group

Information materials

- IF YES, specify content
 - Health condition
 - Options
 - Benefits
 - Risks
 - Probabilities of benefits/risks
 - Help considering the personal importance of benefits versus risks
 - Guidance in the steps of deliberation and communication
 - Other, specify
- IF YES, specify format
 - Booklet, pamphlets
 - Internet
 - Videos/DVDs
 - Other, specify

13. Is there anything else that would help better support you in decision making?

CPM Questionnaire Associated Ottawa Decision Support Framework Variable

Framework Class	Framework Variable	Interview Question #
Decisional Needs	Decision type, time, stage, leaning	1,2,3, 6
	Decisional conflict-uncertain	4
	Values	5
	Support, Resources	5, 7
	Knowledge, expectations	5
	Personal/ Clinical characteristics	Retrieved through retrospective chart review.
Decisional Support	-Clarify decision and needs	8, 9, 10, 11, 12, 13
	-Provide facts, probabilities	
	-Clarify values	
	-Guide/coach/support skills	
Decisional Quality	Monitored use of decision aids, quality of decision support, and patient outcomes will be assessed in future work, following development of resource supports.	