

**Breast Cancer Treatment
Population Needs Assessment Questions
(Consumer/Patient Group Version)**

The Comprehensive Breast Program and the Center for Shared Decision Making at Dartmouth-Hitchcock Medical Center are conducting a survey to learn more about the needs of people when they are making decisions about treatment for breast cancer.

This information will help us to provide counseling and support for people facing these decisions. All of the information we collect in this voluntary survey will be kept confidential. We'd like your help; it will take about 15 minutes of our time.

I'm going to give you some examples of health decisions people with breast cancer face. For example, some people need to make decisions about:

1. the kind of surgery to have (lumpectomy or mastectomy)
2. whether or not to have reconstructive surgery after mastectomy
3. whether or not to have radiation therapy
4. whether or not to have chemotherapy
5. what kind of chemotherapy to have
6. whether or not to take Tamoxifen or other similar medications

PERCEPTION OF AN IMPORTANT DECISION

1. At this time, what do you think are the most important decisions people with newly diagnosed breast cancer face?

2. Let's focus on one decision...one that you think is important and difficult for patients with breast cancer to make. Which one would you choose?

3. Let's talk about the difficulty people have making this decision about breast cancer treatment. How do people feel when making this decision?

[Probe: Do people feel: unsure about what to do worried what could go wrong distressed or upset constantly thinking about the decision wavering between choices or changing your mind delaying the decision questioning what is important to you feeling physically stressed [tense muscles, racing heartbeat, difficulty sleeping]

4. What things makes this decision even more difficult?

[Probe:
Are people: lacking information about options, pros and cons lacking information on the chances of benefits and harms unclear about what is important to you lacking information on what others decide feeling pressure from others lacking support from others lacking motivation or not feeling ready to make a decision
 lacking the skill or ability to make this type of decision other

5. Thinking about this decision, what are the options people face?

6. What are the main pros (advantages) and cons (disadvantages) of the options?

PERCEPTION OF OTHERS

7. Who else may be involved in making this decision?

[Probe:

How are they usually involved in making this choice... are they: making the decision for the patient, sharing the decision with the patient, providing support or advice for the patient to make the decision on their own

RESOURCES

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

[Probe:

Do they: get information on choices get information on how likely the choices are consider how important choices are, get information on how others decide or recommend find ways to handle pressure get support from others other]

9. What helps people to make this decision?

10. What hinders people (gets in the way of) making this decision?

11. What would be helpful to overcome some of the things that hinder (get in the way of) people's decision making?

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

Counseling from health practitioner, IF YES, what type of practitioner _____

Discussion groups of people facing the same decisions, IF YES, what type of organization or group _____

Information materials

If yes, type of medium----> booklets, pamphlets videos CD ROMS
 Internet other, specify _____

If yes, who do you think should prepare information about the decision

pharmacies health societies (Cancer Society, Heart and Stroke Society)

expert medical and health practitioners government

consumer associations

private companies that produce and sell
drugs and health products

insurance companies

CHARACTERISTICS

13. Age Category teens twenties thirties forties fifties sixties seventies
eighties or more

14. Sex male female

15. Duration of experience with health problem _____

16. Role as key informant regarding this health issue _____