

Appendix: Oncology Nurse Navigator Needs Assessment Survey

1. Are you currently providing navigation services to breast cancer patients?

- Yes
- No

2. In the last 6 months in your practice, how many women would you estimate you have provided navigation services to who were diagnosed with breast cancer at age 45 or younger?

- None
- 1-4
- 5-9
- 10-19
- 20 or more

3. In the last 6 months in your practice, how many women would you estimate you have seen who were diagnosed with metastatic breast cancer?

- None
- 1-4
- 5-9
- 10-19
- 20 or more

4. For which of the following topics are you familiar with **any** guidelines, interventions, medical options or resources available for women diagnosed with breast cancer? (Please select all that apply)

- Breast reconstruction
- Cancer preventive services
- Clinical trial participation
- Fatigue
- Fertility preservation
- Financial issues
- Genetic counseling and testing for inherited mutations
- Healthy lifestyles
- Long-term health issues (e.g., cardiovascular health, bone health, neuropathy, etc.)
- Menopause management
- Mental health (e.g., depression, anxiety, distress, etc.)
- Pain management
- Palliative care
- Sexual health or intimacy
- Tumor biomarker testing
- Targeted therapy
- Other (please specify) _____

5. In your navigation work in the last 6 months, how many times would you estimate that you facilitated a referral of young women with breast cancer or metastatic breast cancer patients to programs, services or experts addressing each of these topics?

For each topic, drop down menu consisted of these options for both young women with breast cancer and women with metastatic breast cancer:

- never
- 1-4 times
- 5-9 times
- 10 or more times
 - Breast reconstruction
 - Cancer prevention
 - Clinical trials
 - Fatigue
 - Fertility preservation
 - Financial issues
 - Genetic counseling and testing for inherited mutations
 - Healthy lifestyles
 - Long-term health issues (e.g., cardiovascular health, bone health, neuropathy, etc.)
 - Menopause management
 - Mental health (e.g., depression, anxiety, distress, etc.)
 - Pain management
 - Palliative care
 - Sexual health or intimacy

6. Please select **up to three** of the most common barriers you have experienced when referring young women with breast cancer or metastatic breast cancer patients to experts/programs/services addressing each of the following.

Options included: financial, patient understanding of value, lack of local programs/providers, language barriers, medical jargon or health literacy, none, have never referred.

- Breast reconstruction
- Cancer prevention
- Clinical trials
- Fatigue
- Fertility preservation
- Financial issues
- Genetic counseling and testing for inherited mutations
- Healthy lifestyles
- Long-term health issues (e.g., cardiovascular health, bone health, neuropathy, etc.)
- Menopause management
- Mental health (e.g., depression, anxiety, distress, etc.)
- Pain management
- Palliative care
- Sexual health or intimacy

7. For which of the following topics do you feel more continuing education opportunities are needed for oncology nurse navigators? (Please select all that apply)

- Alcohol and tobacco
- Breast cancer treatments
- Breast reconstruction
- Cancer preventive services
- Clinical trials
- Complementary or alternative medicine
- Communicating using plain language techniques
- Direct-to-consumer genetic testing
- Environmental exposures and breast cancer risk
- Fatigue
- Fertility preservation
- Financial issues
- Genetic counseling and testing for inherited mutations
- Gender minority issues
- Health disparities
- Health literacy
- Healthy lifestyles
- Impact on family, relatives or caregivers
- Long-term health issues (e.g., cardiovascular health, bone health, neuropathy, etc.)
- Lymphedema
- Menopause management
- Mental health (e.g., depression, anxiety, distress, etc.)
- Pain management
- Palliative care
- Risk for recurrence
- Risk for other diseases
- Sexual health or intimacy
- Targeted therapies
- Techniques for communicating with patients in plain language
- Treatment side effects
- Tumor biomarker testing
- Other (please specify) _____

8. For which of the following topics do you feel more patient education materials are needed? (Please select all that apply)

- Alcohol and tobacco
- Breast cancer treatments
- Breast reconstruction
- Cancer preventive services
- Clinical trials
- Complementary or alternative medicine
- Direct-to-consumer genetic testing
- Environmental exposures and breast cancer risk

- Fatigue
- Fertility preservation
- Financial issues
- Gender minority issues
- Genetic counseling and testing for inherited mutations
- Health disparities
- Healthy literacy
- Healthy lifestyles
- Impact on family, relatives or caregivers
- Long-term health issues (e.g., cardiovascular health, bone health, neuropathy, etc.)
- Lymphedema
- Menopause management
- Mental health (e.g., depression, anxiety, distress, etc.)
- Pain management
- Palliative care
- Risk for recurrence
- Risk for other diseases
- Sexual health or intimacy
- Targeted therapies
- Treatment side effects
- Tumor biomarker testing
- Other (please specify) _____

9. In the last six months, how many of your breast cancer patients asked you about media articles or stories they saw online about breast cancer?

- None
- 1-4
- 5-9
- 10 or more

10. How confident do you feel about addressing patients' questions about media articles on breast cancer?

- Very confident
- Somewhat confident
- Not very confident
- Not at all confident
- I'm not certain

11. Please use the following scale to tell us how useful the following types of information would be for helping you to feel more confident discussing media articles covering specific breast cancer topics with patients.

Options for each type of information:

- Very useful
- Somewhat useful
- Not very useful
- Not at all useful
- I'm not certain

Types of information:

- Information about discussing the relevance of the research to clinical care.
- Information about discussing the quality of the media reporting.
- Information about discussing research design and limitations.
- Information about any current guidelines related to the topic.
- Other

12. Are you familiar with the FORCE program called eXamining the Relevance of Articles for You (XRAY) Program which provides summaries of cancer research covered by the media?

- Yes
- No
- Unsure

13. How helpful have you found each of following features of XRAY reviews in your communication with patients or other aspects of your work?

Options for each feature:

- Not helpful at all
- Neutral

- Somewhat helpful
- Very helpful
- Have not used
- Features:
 - > Summary
 - > Research timeline
 - > Who the article is relevant for
 - > Relevance score
 - > In-depth coverage of journal article
 - > Media coverage and ratings
 - > Expert guidelines
 - > Questions for your provider
 - > Clinical trials
 - > Printer friendly version

14. If we were to design a version of XRAY specifically for oncology navigators, how helpful would each of the following features be in your practice?

Options for each feature:

- Not helpful at all
- Neutral
- Somewhat helpful
- Very helpful

Features:

- > Questions most asked by patients
- > Links to opportunities for continuing education related to the article topic
- > List of patient programs and services related to the topic
- > Key issues to highlight for patients
- > Other (please specify)

15. Do you have an example of a situation where you wished you had more information or services available to address a patient's needs that you would like to share with us? (open response)

16. What is your role as an oncology navigator? (Please select all that apply)

- I am a licensed nurse
- I am a licensed social worker
- I am an unlicensed community health worker
- I work at an academic institution
- I work at a community cancer center
- I work at a VA
- I work at a federally qualified health center
- I work for a nonprofit organization
- I work in industry
- I work for a professional society
- I am a volunteer
- I have been a navigator for less than a year
- I have been a navigator for 1-2 years
- I have been a navigator for 3-5 years
- I have been a navigator for over 5 years
- I work in a rural setting

17. Please provide any additional comments you wish to share with us.