

BREAST CANCER SURVIVORSHIP REHABILITATION INITIATIVE

COMMUNITY REPORT APPENDICES

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SUPPORT FOR THE BREAST CANCER SURVIVORSHIP
REHABILITATION INITIATIVE COMES FROM THE WOMEN'S
BREAST HEALTH FUND OF THE COMMUNITY FOUNDATION OF
GREATER BIRMINGHAM AS PART OF AN EFFORT TO IMPROVE
THE QUALITY OF LIFE FOR WOMEN WHO ARE BREAST CANCER
SURVIVORS AS WELL AS THEIR LOVED ONES.

Breast Cancer Survivorship Rehabilitation Initiative

Community Report Appendices

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Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

A. Introduction

Introduction and Purpose:

This survey is one component of an evaluation of **breast cancer survivorship** services in the Greater Birmingham area, including Blount, Jefferson, Shelby, St. Clair, and Walker counties. The Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) is a collaboration of the Community Foundation of Greater Birmingham, Baptist Health System, Brookwood Medical Center, St. Vincent's Health System, Trinity Medical Center, UAB Medicine and UAB School of Nursing. Our primary goal is to evaluate, discern, and develop a community-based, patient-centered comprehensive program to assist survivors and their families that have faced a breast cancer diagnosis. It is our vision that this program will:

- Provide proactive rehabilitation in order to reduce comorbid conditions such as heart disease, osteoporosis, etc.
- Promote physical health and quality of life through lifestyle intervention programs
- Eliminate gaps and fragmentation in care following breast cancer treatment
- Reduce costs for both the institutions and care recipients

Completing this survey will take 20-30 minutes of your time. In addition, if you are willing, a one-to-one telephone interview will be scheduled at your convenience to further discuss breast cancer survivorship services.

What rights do I have as a survey participant?

Taking part in this survey is completely voluntary. You will have the option to decline to answer questions that identify you, and you can choose to stop the survey at any time. You will also have the option of not submitting the survey. However, once you submit your answers, you will not be able to withdraw your responses.

Are there any costs related to this survey and will I be paid to take part in this survey?

There is no cost to you for taking part in this survey. You will not be paid to participate in this survey.

Are there any benefits or risks to participating in this survey?

You will not receive any direct benefits from taking part in this survey. However, the knowledge gained from this survey will improve programs for breast cancer survivors in the greater Birmingham area.

How will my privacy be protected and my information kept confidential?

The BCSRI has mechanisms in place to protect your privacy and confidentiality. We will give you the option to include your name, address and an email address separately from the survey so that we can contact you for a one-on-one telephone interview if you are willing to participate. However, your contact information will NOT be stored with data from your survey. Instead, you will be assigned a participant number and only the participant number will appear with your survey responses. Only the assessment team will see your individual survey responses. Identifiable health information, or Protected Health Information (PHI), is covered by the Privacy Rule (HIPAA). By agreeing to participate in this survey you are also authorizing the use of this information as described below.

We will collect PHI in this survey. The survey you return to the BCSRI team will be kept in a locked file cabinet separate from your contact information. The answers you provide will be entered and stored on secure servers at SurveyGizmo using security safeguards that are compliant with HIPAA law. The information will be stored in an electronic, secure database on a password-protected computer at BCSRI. Once the results of the assessment have been analyzed, all individual participant identifiers will be destroyed. The individual health information you provide will not be shared outside of the assessment team.

Who should I call with questions about the assessment?

Rebecca Di Piazza
Breast Cancer Survivorship Rehabilitation Initiative
1 Medical Park East Drive
Birmingham, AL 35235
(205) 838-6169
Rebecca.DiPiazza@stvhs.com

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

A. Introduction (cont...)

Consent to Participate and Authorization to Use and Disclose Protected Health Information

I have read this consent document before accessing and completing any surveys or questionnaires. I have had the opportunity to contact a designated representative to ask questions. I authorize the use and disclosure of my protected health information as outlined in this form. My consent to participate in this survey has been given freely and willingly. I confirm that I am 19 years of age or older.

Signature _____ Date _____

Please be open and candid with your answers and submit this survey by **March 31, 2015.**

TOGETHER WE CAN MAKE A DIFFERENCE IN OUR BREAST CANCER COMMUNITY!

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

B. General Information

1. In which county do you reside?

- Blount
- Jefferson
- Shelby
- St. Clair
- Walker
- Other

2. Where did you hear about the survey?

- Health System
- Support Group
- Church
- Special Event

Other (please specify) _____

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

C. Demographics

1. What is your age?

- | | |
|-----------------------------------|----------------------------------|
| <input type="checkbox"/> Under 30 | <input type="checkbox"/> 51-60 |
| <input type="checkbox"/> 31-40 | <input type="checkbox"/> Over 60 |
| <input type="checkbox"/> 41-50 | |

2. What is your gender?

- Male
- Female

3. What category best describes your race?

- | | |
|---|--|
| <input type="checkbox"/> White | <input type="checkbox"/> Filipino |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Japanese |
| <input type="checkbox"/> American Indian or Alaska Native | <input type="checkbox"/> Korean |
| <input type="checkbox"/> Native Hawaiian | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Guamanian or Chamorro |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Samoan |

Other (please specify) _____

4. Are you Hispanic, Latino, or Spanish origin?

- | | |
|--|--|
| <input type="checkbox"/> No, not of Hispanic, Latino or Spanish origin | <input type="checkbox"/> Yes, Puerto Rican |
| <input type="checkbox"/> Yes, Mexican, Mexican American, Chicano | <input type="checkbox"/> Yes, Cuban |
| <input type="checkbox"/> Yes, other Hispanic, Latino, or Spanish origin (please specify) _____ | |

5. Are you a breast cancer survivor?

- Yes
- No

IF NO, PLEASE GO TO QUESTION #11

6. At what age were you diagnosed?

- | | |
|-----------------------------------|--|
| <input type="checkbox"/> Under 30 | <input type="checkbox"/> 51-60 |
| <input type="checkbox"/> 31-40 | <input type="checkbox"/> Over 60 |
| <input type="checkbox"/> 41-50 | <input type="checkbox"/> I choose not to respond |

7. My stage of treatment is:

- | | |
|---|---|
| <input type="checkbox"/> Newly diagnosed | <input type="checkbox"/> Finished treatment less than 5 years ago |
| <input type="checkbox"/> Currently in treatment including adjuvant treatment (ie. hormonal therapy, Herceptin, Tamoxifen, etc...) | <input type="checkbox"/> Finished treatment more than 5 years ago |
| | <input type="checkbox"/> I don't know |

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

C. Demographics (cont...)

8. Who advised you of your diagnosis?

- | | |
|---|--|
| <input type="checkbox"/> Nurse Practitioner/Physician Assistant | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Gynecologist | <input type="checkbox"/> Other Health Professional |
| <input type="checkbox"/> Surgeon | <input type="checkbox"/> Radiologist |
| <input type="checkbox"/> Internist | <input type="checkbox"/> Oncologist |

Other (please specify) _____

9. When you were advised of your diagnosis, how were you told?

- In person
- By phone
- By letter
- By e-mail

Other (please specify) _____

10. When you were advised of your diagnosis, what resources if any, were you offered?

11. Who do you know that has been diagnosed with breast cancer? Please select all that apply.

- | | |
|--------------------------------------|--|
| <input type="checkbox"/> Mother | <input type="checkbox"/> Niece |
| <input type="checkbox"/> Grandmother | <input type="checkbox"/> Spouse |
| <input type="checkbox"/> Sister | <input type="checkbox"/> Partner |
| <input type="checkbox"/> Daughter | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Aunt | <input type="checkbox"/> No one, just me |

Other (please specify): _____

12. Are you or have you ever been a caregiver for a family member or friend with breast cancer?

- Yes
- No

13. Are you also a healthcare professional?

- Yes
- No

If YES you are a healthcare professional, please continue to answer the survey as a survivor/co-survivor rather than a healthcare professional. If you prefer to complete the healthcare professional survey please contact the project director at rebecca.dipiazza@stvhs.com. If NO you are not a healthcare professional, continue on to the next section.

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

D. Health Issues

1. Who are the most credible people that provide GENERAL health information in your community? Please select up to 5.
- | | |
|---|---|
| <input type="checkbox"/> Pharmacists | <input type="checkbox"/> Non-traditional healers |
| <input type="checkbox"/> Nurse Practitioners/Physician Assistants | <input type="checkbox"/> Other health professionals e.g. midwives, social workers, etc. |
| <input type="checkbox"/> Non-Profits/ community organizations | <input type="checkbox"/> Clinic administrative staff |
| <input type="checkbox"/> Family members | <input type="checkbox"/> Medical doctors |
| <input type="checkbox"/> Hospital staff/representatives | <input type="checkbox"/> County Health Department |
| <input type="checkbox"/> Friends | <input type="checkbox"/> Nurses |
| <input type="checkbox"/> Religious leaders | |
- Other (please specify) _____
2. Where is someone in your community most likely to go for BREAST CANCER SURVIVORSHIP information? Please select up to 5.
- | | |
|---|---|
| <input type="checkbox"/> Friends | <input type="checkbox"/> Religious leaders |
| <input type="checkbox"/> Pharmacists | <input type="checkbox"/> Clinic administrative staff |
| <input type="checkbox"/> County Health Department | <input type="checkbox"/> Family members |
| <input type="checkbox"/> Non-profits/community organizations | <input type="checkbox"/> Medical doctors |
| <input type="checkbox"/> Nurse practitioners/Physician Assistants | <input type="checkbox"/> Other health professionals e.g. midwives, social workers, etc. |
| <input type="checkbox"/> Non-traditional healers | <input type="checkbox"/> Internet |
| <input type="checkbox"/> Nurses | <input type="checkbox"/> Mobile applications |
| <input type="checkbox"/> Hospital staff/representatives | |
| <input type="checkbox"/> Breast cancer survivors | |
- Other (please specify) _____
3. What is the most effective way to disseminate breast cancer survivorship information in your community? Please select up to 5.
- | | |
|--|--|
| <input type="checkbox"/> Health fairs and other community events | <input type="checkbox"/> Churches |
| <input type="checkbox"/> Internet | <input type="checkbox"/> Newspaper |
| <input type="checkbox"/> Friends/word of mouth | <input type="checkbox"/> Billboards |
| <input type="checkbox"/> Videos | <input type="checkbox"/> Radio |
| <input type="checkbox"/> Schools | <input type="checkbox"/> Television |
| <input type="checkbox"/> Brochures and pamphlets | <input type="checkbox"/> Mobile applications |
| <input type="checkbox"/> Public presentations | |
- Other (please specify) _____

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

D. Health Issues (cont...)

4. Are there particular groups in your community that have a great need for breast cancer survivorship services? Please select up to 5.
- | | |
|--|---|
| <input type="checkbox"/> White | <input type="checkbox"/> Individuals aged 65-74 |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Individuals aged 75-85 |
| <input type="checkbox"/> American Indian or Alaskan Native | <input type="checkbox"/> Individuals aged 86 and older |
| <input type="checkbox"/> Asian | <input type="checkbox"/> Low income individuals |
| <input type="checkbox"/> Native Hawaiian or other Pacific Islander | <input type="checkbox"/> Individuals who are uninsured or underinsured |
| <input type="checkbox"/> Hispanic/Latino individuals | <input type="checkbox"/> Individuals living in rural areas |
| <input type="checkbox"/> Individuals under age 40 | <input type="checkbox"/> All have the same needs regardless of race, ethnicity, age, etc. |
| <input type="checkbox"/> Individuals aged 40-49 | |
| <input type="checkbox"/> Individuals aged 50-64 | |

Other (please specify) _____

5. Is there a group in your community that speaks English as a second language that needs breast cancer survivorship services?
- Yes
 No
 Not sure

IF NO OR NOT SURE, PLEASE GO TO QUESTION #7

6. What language does this group speak?
- Spanish or Spanish Creole
 Other Indo European Language
 Asian or Pacific Islander Language

Other (please specify): _____

7. Are breast cancer survivorship materials available in your community in languages other than English?
- Yes
 No
 Not sure

If yes, what languages? (please specify) _____

8. Is there a need for interpreters who can provide breast cancer survivorship education in your community?
- Yes
 No
 Not sure

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

E. Obstacles and Barriers to Care

1. Which of the following are obstacles and barriers to cancer survivorship care in your community in regards to ACCESS? Please select up to 3.

- | | |
|---|--|
| <input type="checkbox"/> Lack of medical providers | <input type="checkbox"/> Limited hours of operation (clinic, hospital, etc.) |
| <input type="checkbox"/> Rural areas | <input type="checkbox"/> No cell phone service |
| <input type="checkbox"/> No services for non-English speakers | <input type="checkbox"/> No public transportation |
| <input type="checkbox"/> Location of services is too far away | <input type="checkbox"/> No computer/internet service available |
| <input type="checkbox"/> Violence/area not safe | |

Other (please specify) _____

2. What can be done to reduce these barriers or improve access to breast cancer survivorship care?

3. Which of the following are obstacles and barriers to breast cancer survivorship care in your community in regards to COST? Please select up to 3.

- | | |
|---|---|
| <input type="checkbox"/> Knowledge/awareness of costs | <input type="checkbox"/> Cannot afford to take off work |
| <input type="checkbox"/> Uninsured/underinsured | <input type="checkbox"/> Cannot afford transportation |
| <input type="checkbox"/> Cannot afford child care | <input type="checkbox"/> Cannot afford survivorship services that are not reimbursed by insurance |
| <input type="checkbox"/> Cannot afford services | |

Other (please specify) _____

4. Which of the following are obstacles and barriers to breast cancer survivorship care in your community in regards to FEAR? Please select up to 3.

- | | |
|--|--|
| <input type="checkbox"/> Going to the doctor | <input type="checkbox"/> Concern about privacy |
| <input type="checkbox"/> Procedures such as a mammogram | <input type="checkbox"/> Pain |
| <input type="checkbox"/> Result of tests | <input type="checkbox"/> Not knowing the doctor well |
| <input type="checkbox"/> Disfigurement e.g. hair loss, losing a breast | <input type="checkbox"/> Not understanding medical terms |
| <input type="checkbox"/> Diagnosis of reoccurrence or secondary cancer | |

Other (please specify) _____

5. Which of the following are obstacles and barriers to breast cancer survivorship care in your community in regards to EDUCATION AND AWARENESS? Please select up to 3.

- | | |
|--|---|
| <input type="checkbox"/> Not recommended by health care professional | <input type="checkbox"/> Not aware of risks for illnesses related to treatments |
| <input type="checkbox"/> Uninformed about preventative care | <input type="checkbox"/> Not discussed with health care professional |
| <input type="checkbox"/> Lack of education and/or low literacy level | <input type="checkbox"/> Myths and false information |
| <input type="checkbox"/> Not aware of programs in the community | <input type="checkbox"/> Not aware of risk for secondary cancers |

Other (please specify) _____

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

E. Obstacles and Barriers to Care (cont...)

6. Which of the following are obstacles and barriers to breast cancer survivorship care in your community in regards to CULTURAL AND BEHAVIORAL FACTORS? Please select up to 3.

- | | |
|---|--|
| <input type="checkbox"/> Embarrassment/modesty | <input type="checkbox"/> Distrust of the medical systems |
| <input type="checkbox"/> Other more urgent problems | <input type="checkbox"/> Forget |
| <input type="checkbox"/> Conflict with religious beliefs | <input type="checkbox"/> Spouse/partner does not approve |
| <input type="checkbox"/> Concerns about privacy | <input type="checkbox"/> Lack of family support |
| <input type="checkbox"/> Put off procedure | |
| <input type="checkbox"/> Lack of social support (friends, etc.) | |

Other (please specify) _____

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

F. Treatment Options and Preferences

1. In your opinion, how important are the following survivorship services in the care of breast cancer survivors?

	Not at all important	Not very important	Somewhat important	Important	Very important
a) Heart health programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Sexuality programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Relaxation training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Prosthesis services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Financial counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Massage therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Psychological counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Exercise and fitness programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Palliative care services/ pain symptom management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Palliative care/end of life services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Fertility counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Personal appearance including makeup and wigs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Aquatic therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) Lymphedema counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) Genetic testing and counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) Bone health programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) Nutrition counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) Spirituality programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

F. Treatment Options and Preferences (cont...)

2. How do most women in your community pay for breast cancer survivorship services? Please select up to 3.

- | | |
|---|--|
| <input type="checkbox"/> Medicaid or Medicare | <input type="checkbox"/> Unable to pay |
| <input type="checkbox"/> Private insurance | <input type="checkbox"/> Cash or check |
| <input type="checkbox"/> Credit card | <input type="checkbox"/> Loan |
| <input type="checkbox"/> Charities | |

Other (please specify) _____

3. Where do low income or underserved women go for breast cancer survivorship services? Please select up to 3.

- | | |
|--|---|
| <input type="checkbox"/> Nurses or other health professional | <input type="checkbox"/> Non-traditional healer |
| <input type="checkbox"/> Physician office or private clinic | <input type="checkbox"/> County Health Department |
| <input type="checkbox"/> Nurse practitioner/ physician assistant | <input type="checkbox"/> Community or public clinic |
| <input type="checkbox"/> Emergency room or hospital | |

Other (please specify) _____

4. In your community, who oversees breast cancer survivors' healthcare? Please select all that apply.

- | | |
|--|---|
| <input type="checkbox"/> Multidisciplinary team of oncology clinicians | <input type="checkbox"/> Internist/Primary Care Physician |
| <input type="checkbox"/> Medical oncologist | <input type="checkbox"/> Radiologist |
| <input type="checkbox"/> Nurse | <input type="checkbox"/> Gynecologist |
| <input type="checkbox"/> Surgeon | <input type="checkbox"/> Radiation oncologist |
| <input type="checkbox"/> Nurse practitioner/physician assistant | |

Other (please specify) _____

5. Do you believe that a large number of breast cancer survivors in your community are not getting recommended follow-up care?

- Yes
 No
 Not sure

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

G. Organizations

1. Are BREAST HEALTH AND DIAGNOSTIC SERVICES available in your county? If NOT, how far away is the closest community?

- Yes
- No
- Not sure

Closest Community:

- <15 miles
- 15-30 miles
- 31-60 miles
- 61-100 miles
- >100 miles

2. Where would you go for BREAST HEALTH AND DIAGNOSTIC SERVICES?

3. Are BREAST CANCER TREATMENT CENTERS available in your county? If not, how far away is the closest community where treatment is available?

- Yes
- No
- Not sure

Closest community:

- <15 miles
- 15-30 miles
- 31-60 miles
- 61-100 miles
- >100 miles

4. Where would you go for BREAST CANCER TREATMENT?

5. What are the most visible or active breast cancer survivorship programs and/or non-profit organizations in your community?

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

G. Organizations (cont...)

6. Do you support any of these organizations in a volunteer capacity?

- Yes
- No

7. What financial resources are available in your community for breast cancer survivorship services?

8. Are there adequate support groups for breast cancer survivors in your community?

- Yes
- No
- Not sure

9. Are there adequate support groups for FAMILY MEMBERS of breast cancer survivors (including children) in your community?

- Yes
- No
- Not sure

10. Are there adequate support groups for CAREGIVERS of breast cancer survivors in your community?

- Yes
- No
- Not sure

11. In your community, when are breast cancer survivors referred back to their primary care physician for health care and cancer surveillance?

- Immediately following primary treatment
- Less than 2 years following primary treatment
- 2-5 years following primary treatment
- 6-10 years following primary treatment
- After 10 years
- Cancer specialists follow survivors for life
- I don't know

12. Is there a program in your community that helps breast cancer survivors navigate the medical system in a way that ensures the patient gets needed services?

- Yes
- No
- Not sure

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

G. Organizations (cont...)

13. What types of navigation are provided and who provides it? Please select all that apply

- | | |
|--|---|
| <input type="checkbox"/> Transportation_____ | <input type="checkbox"/> Prosthesis, wigs and/or bra_____ |
| <input type="checkbox"/> Financial assistance_____ | <input type="checkbox"/> Medicaid_____ |
| <input type="checkbox"/> Support services_____ | <input type="checkbox"/> Lymphedema Products_____ |
| <input type="checkbox"/> Not sure | |

Other (please specify)_____

14. What additional support services are offered to breast cancer survivors in your community? Please select all that apply:

- | | |
|--|--|
| <input type="checkbox"/> Exercise and fitness programs | <input type="checkbox"/> Nutrition counseling |
| <input type="checkbox"/> Personal appearance including makeup and wigs | <input type="checkbox"/> Bone health programs |
| <input type="checkbox"/> Massage therapy | <input type="checkbox"/> Lymphedema counseling |
| <input type="checkbox"/> Spirituality programs | <input type="checkbox"/> Fertility counseling |
| <input type="checkbox"/> Psychological counseling | <input type="checkbox"/> Palliative care services/ pain symptom management |
| <input type="checkbox"/> Financial counseling | <input type="checkbox"/> Palliative care/end of life services |
| <input type="checkbox"/> Aquatic therapy | <input type="checkbox"/> Relaxation training |
| <input type="checkbox"/> Sexuality programs | <input type="checkbox"/> Heart health programs |
| <input type="checkbox"/> Genetic testing and counseling | |
| <input type="checkbox"/> Prosthesis services | |

Other (please specify)_____

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

G. Organizations (cont...)

15. In your community, which of the following PRACTICAL PROBLEMS have the greatest need for support in regards to breast cancer survivors? Please select up to 3.
- Child care
 - Housing
 - Insurance/financial
 - Transportation
 - Work/school
 - Treatment decisions
16. In your community, which of the following FAMILY PROBLEMS have the greatest need for support in regards to breast cancer survivors? Please select up to 3.
- Dealing with children
 - Dealing with partner
 - Ability to have children
 - Family health issues
17. In your community, which of the following EMOTIONAL PROBLEMS have the greatest need for support in regards to breast cancer survivors? Please select up to 3.
- Depression
 - Fears
 - Nervousness
 - Sadness
 - Worry
 - Loss of interest in usual activities
 - Spiritual/religious concerns
18. In your community, which of the following PHYSICAL PROBLEMS have the greatest need for support in regards to breast cancer survivors? Please select up to 5.
- | | |
|---|---|
| <input type="checkbox"/> Appearance | <input type="checkbox"/> Indigestion |
| <input type="checkbox"/> Bathing/dressing | <input type="checkbox"/> Memory/concentration |
| <input type="checkbox"/> Breathing | <input type="checkbox"/> Mouth sores |
| <input type="checkbox"/> Changes in urination | <input type="checkbox"/> Nausea |
| <input type="checkbox"/> Constipation | <input type="checkbox"/> Nose dry/congested |
| <input type="checkbox"/> Diarrhea | <input type="checkbox"/> Pain |
| <input type="checkbox"/> Eating | <input type="checkbox"/> Sexual |
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Skin dry/itchy |
| <input type="checkbox"/> Feeling swollen | <input type="checkbox"/> Sleep |
| <input type="checkbox"/> Fevers | <input type="checkbox"/> Substance abuse |
| <input type="checkbox"/> Getting around | <input type="checkbox"/> Tingling in hands/feet |

Appendix A: Surveys

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survivor and Co-Survivor Survey

H. Conclusion

If you are willing to participate in a one-on-one telephone interview scheduled at your convenience:

- **Please fill out and submit the provided, separate contact information form by March 31, 2015**
- **Mail CONTACT information form with the envelope provided, by March 31, 2015 to:**
Rebecca Di Piazza
Breast Cancer Survivorship Rehabilitation Initiative
St. Vincent's Foundation of Alabama, Inc.
1 Medical Park East Drive
Birmingham, AL 35235
- **Mail completed SURVEY with the envelope provided, by March 31, 2015 to:**
Alia Tunagur
Breast Cancer Survivorship Rehabilitation Initiative
St. Vincent's Foundation of Alabama, Inc.
1 Medical Park East Drive
Birmingham, AL 35235

Appendix A: Surveys

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

A. Introduction

Introduction and Purpose:

This survey is one component of an evaluation of **breast cancer survivorship** services in the Greater Birmingham area, including Blount, Jefferson, Shelby, St. Clair, and Walker counties. The Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) is a collaboration of the Community Foundation of Greater Birmingham, Baptist Health System, Brookwood Medical Center, St. Vincent's Health System, Trinity Medical Center, UAB Medicine and UAB School of Nursing. Our primary goal is to evaluate, discern, and develop a community-based, patient-centered comprehensive program to assist survivors and their families that have faced a breast cancer diagnosis. It is our vision that this program will:

- Provide proactive rehabilitation in order to reduce comorbid conditions such as heart disease, osteoporosis, etc.
- Promote physical health and quality of life through lifestyle intervention programs
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Completing this survey will take 20-30 minutes of your time. In addition, if you are willing, a one-to-one telephone interview will be scheduled at your convenience to further discuss breast cancer survivorship services.

What rights do I have as a survey participant?

Taking part in this survey is completely voluntary. You will have the option to decline to answer questions that identify you, and you can choose to stop the survey at any time. You will also have the option of not submitting the survey. However, once you submit your answers, you will not be able to withdraw your responses.

Are there any costs related to this survey and will I be paid to take part in this survey?

There is no cost to you for taking part in this survey. You will not be paid to participate in this survey.

Are there any benefits or risks to participating in this survey?

You will not receive any direct benefits from taking part in this survey. However, the knowledge gained from this survey will improve programs for breast cancer survivors in the greater Birmingham area.

How will my privacy be protected and my information kept confidential?

The BCSRI has mechanisms in place to protect your privacy and confidentiality. We will give you the option to include your name, address and an email address separately from the survey so that we can contact you for a one-on-one telephone interview if you are willing to participate. However, your contact information will NOT be stored with data from your survey. Instead, you will be assigned a participant number and only the participant number will appear with your survey responses. Only the assessment team will see your individual survey responses. Identifiable health information, or Protected Health Information (PHI), is covered by the Privacy Rule (HIPAA). By agreeing to participate in this survey you are also authorizing the use of this information as described below.

We will collect PHI in this survey. The survey you return to the BCSRI team will be kept in a locked file cabinet. The answers you provide will be entered and stored on secure servers at SurveyGizmo using security safeguards that are compliant with HIPAA law. The information will be stored in an electronic, secure database on a password-protected computer at BCSRI. Once the results of the assessment have been analyzed, all individual participant identifiers will be destroyed. The individual health information you provide will not be shared outside of the assessment team.

Who should I call with questions about the assessment?

Rebecca Di Piazza
Breast Cancer Survivorship Rehabilitation Initiative
1 Medical Park East Drive
Birmingham, AL 35235
(205) 838-6169
Rebecca.DiPiazza@stvhs.com

Appendix A: Surveys

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

A. Introduction (cont...)

Consent to Participate and Authorization to Use and Disclose Protected Health Information

I have read this consent document before accessing and completing any surveys or questionnaires. I have had the opportunity to contact a designated representative to ask questions. I authorize the use and disclosure of my protected health information as outlined in this form. My consent to participate in this survey has been given freely and willingly. I confirm that I am 19 years of age or older.

Signature _____ Date _____

Please be open and candid with your answers and submit this survey by **March 31, 2015.**

TOGETHER WE CAN MAKE A DIFFERENCE IN OUR BREAST CANCER COMMUNITY!

Appendix A: Surveys

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

B. General Information

3. In which county do you reside?

- Blount
- Jefferson
- Shelby
- St. Clair
- Walker
- Other

4. Where did you hear about the survey?

- Health System
- Support Group
- Church
- Special Event

Other (please specify) _____

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

C. Demographics

PLEASE ANSWER AS A HEALTHCARE PROFESSIONAL

14. What is your age?

- | | |
|-----------------------------------|----------------------------------|
| <input type="checkbox"/> Under 30 | <input type="checkbox"/> 51-60 |
| <input type="checkbox"/> 31-40 | <input type="checkbox"/> Over 60 |
| <input type="checkbox"/> 41-50 | |

15. What is your gender?

- Male
- Female

16. What category best describes your race?

- | | | |
|---|---------------------------------------|--|
| <input type="checkbox"/> White | <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Chinese | <input type="checkbox"/> Guamanian or Chamorro |
| <input type="checkbox"/> American Indian or Alaska Native | <input type="checkbox"/> Filipino | <input type="checkbox"/> Samoan |
| <input type="checkbox"/> Native Hawaiian | <input type="checkbox"/> Japanese | |
| | <input type="checkbox"/> Korean | |

Other (please specify) _____

17. Are you Hispanic, Latino, or Spanish origin?

- | | |
|--|--|
| <input type="checkbox"/> No, not of Hispanic, Latino or Spanish origin | <input type="checkbox"/> Yes, Puerto Rican |
| <input type="checkbox"/> Yes, Mexican, Mexican American, Chicano | <input type="checkbox"/> Yes, Cuban |
| <input type="checkbox"/> Yes, other Hispanic, Latino, or Spanish origin (please specify) _____ | |

18. Are you a breast cancer survivor?

- Yes
- No

If YES you are a breast cancer survivor, please continue to answer the survey as a healthcare professional rather than a survivor. If you prefer to complete the survivor/co-survivor survey please contact the project director at rebecca.dipiazza@stvhs.com. If NO you are not a breast cancer survivor, continue on to question #6.

19. Who do you know that has been diagnosed with breast cancer? Please select all that apply.

- | | |
|--------------------------------------|--|
| <input type="checkbox"/> Mother | <input type="checkbox"/> Niece |
| <input type="checkbox"/> Grandmother | <input type="checkbox"/> Spouse |
| <input type="checkbox"/> Sister | <input type="checkbox"/> Partner |
| <input type="checkbox"/> Daughter | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Aunt | <input type="checkbox"/> No one, just me |

Other (please specify): _____

20. Are you or have you ever been a caregiver for a family member or friend with breast cancer?

- Yes
- No

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

D. Health Issues

9. Who are the most credible people that provide GENERAL health information? Please select up to 5.

- | | |
|---|---|
| <input type="checkbox"/> Pharmacists | <input type="checkbox"/> Non-traditional healers |
| <input type="checkbox"/> Nurse Practitioners/Physician Assistants | <input type="checkbox"/> Other health professionals e.g. midwives, social workers, etc. |
| <input type="checkbox"/> Non-Profits/ community organizations | <input type="checkbox"/> Clinic administrative staff |
| <input type="checkbox"/> Family members | <input type="checkbox"/> Medical doctors |
| <input type="checkbox"/> Hospital staff/representatives | <input type="checkbox"/> County Health Department |
| <input type="checkbox"/> Friends | <input type="checkbox"/> Nurses |
| <input type="checkbox"/> Religious leaders | |

Other (please specify) _____

10. Where is someone most likely to go for BREAST CANCER SURVIVORSHIP information? Please select up to 5.

- | | |
|---|---|
| <input type="checkbox"/> Friends | <input type="checkbox"/> Religious leaders |
| <input type="checkbox"/> Pharmacists | <input type="checkbox"/> Clinic administrative staff |
| <input type="checkbox"/> County Health Department | <input type="checkbox"/> Family members |
| <input type="checkbox"/> Non-profits/community organizations | <input type="checkbox"/> Medical doctors |
| <input type="checkbox"/> Nurse practitioners/Physician Assistants | <input type="checkbox"/> Other health professionals e.g. midwives, social workers, etc. |
| <input type="checkbox"/> Non-traditional healers | <input type="checkbox"/> Internet |
| <input type="checkbox"/> Nurses | <input type="checkbox"/> Mobile Applications |
| <input type="checkbox"/> Hospital staff/representatives | |
| <input type="checkbox"/> Breast cancer survivors | |

Other (please specify) _____

11. What is the most effective way to disseminate breast cancer survivorship information? Please select up to 5.

- | | |
|--|--|
| <input type="checkbox"/> Health fairs and other community events | <input type="checkbox"/> Churches |
| <input type="checkbox"/> Internet | <input type="checkbox"/> Newspaper |
| <input type="checkbox"/> Friends/word of mouth | <input type="checkbox"/> Billboards |
| <input type="checkbox"/> Videos | <input type="checkbox"/> Radio |
| <input type="checkbox"/> Schools | <input type="checkbox"/> Television |
| <input type="checkbox"/> Brochures and pamphlets | <input type="checkbox"/> Mobile Applications |
| <input type="checkbox"/> Public presentations | |

Other (please specify) _____

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

D. Health Issues (cont...)

12. Are there particular groups that have a great need for breast cancer survivorship services? Please select up to 5.

- | | |
|--|---|
| <input type="checkbox"/> White | <input type="checkbox"/> Individuals aged 65-74 |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Individuals aged 75-85 |
| <input type="checkbox"/> American Indian or Alaskan Native | <input type="checkbox"/> Individuals aged 86 and older |
| <input type="checkbox"/> Asian | <input type="checkbox"/> Low income individuals |
| <input type="checkbox"/> Native Hawaiian or other Pacific Islander | <input type="checkbox"/> Individuals who are uninsured or underinsured |
| <input type="checkbox"/> Hispanic/Latino individuals | <input type="checkbox"/> Individuals living in rural areas |
| <input type="checkbox"/> Individuals under age 40 | <input type="checkbox"/> All have the same needs regardless of race, ethnicity, age, etc. |
| <input type="checkbox"/> Individuals aged 40-49 | |
| <input type="checkbox"/> Individuals aged 50-64 | |

Other (please specify) _____

13. Is there a group that speaks English as a second language that needs breast cancer survivorship services?

- Yes
 No
 Not sure

IF NO OR NOT SURE, PLEASE GO TO QUESTION #7

14. What language does this group speak?

- Spanish or Spanish Creole
 Other Indo European Language
 Asian or Pacific Islander Language

Other (please specify): _____

15. In the community that you serve, are breast cancer survivorship materials available in languages other than English?

- Yes
 No
 Not sure

If yes, what languages? (please specify) _____

16. Is there a need for interpreters who can provide breast cancer survivorship education?

- Yes
 No
 Not sure

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

E. Obstacles and Barriers to Care

7. Which of the following are obstacles and barriers to breast cancer survivorship care in regards to ACCESS? Please select up to 3.

- | | |
|---|--|
| <input type="checkbox"/> Lack of medical providers | <input type="checkbox"/> Limited hours of operation (clinic, hospital, etc.) |
| <input type="checkbox"/> Rural areas | <input type="checkbox"/> No cell phone service |
| <input type="checkbox"/> No services for non-English speakers | <input type="checkbox"/> No public transportation |
| <input type="checkbox"/> Location of services is too far away | <input type="checkbox"/> No computer/internet service available |
| <input type="checkbox"/> Violence/area not safe | |

Other (please specify) _____

8. What can be done to reduce these barriers or improve access to breast cancer survivorship care?

9. Which of the following are obstacles and barriers to breast cancer survivorship care in regards to COST? Please select up to 3.

- | | |
|---|---|
| <input type="checkbox"/> Knowledge/awareness of costs | <input type="checkbox"/> Cannot afford to take off work |
| <input type="checkbox"/> Uninsured/underinsured | <input type="checkbox"/> Cannot afford transportation |
| <input type="checkbox"/> Cannot afford child care | <input type="checkbox"/> Cannot afford survivorship services that are not reimbursed by insurance |
| <input type="checkbox"/> Cannot afford services | |

Other (please specify) _____

10. Which of the following are obstacles and barriers to breast cancer survivorship care in regards to FEAR? Please select up to 3.

- | | |
|--|--|
| <input type="checkbox"/> Going to the doctor | <input type="checkbox"/> Concern about privacy |
| <input type="checkbox"/> Procedures such as a mammogram | <input type="checkbox"/> Pain |
| <input type="checkbox"/> Result of tests | <input type="checkbox"/> Not knowing the doctor well |
| <input type="checkbox"/> Disfigurement e.g. hair loss, losing a breast | <input type="checkbox"/> Not understanding medical terms |
| <input type="checkbox"/> Diagnosis of reoccurrence or secondary cancer | |

Other (please specify) _____

11. Which of the following are obstacles and barriers to breast cancer survivorship care in regards to EDUCATION AND AWARENESS? Please select up to 3.

- | | |
|--|--|
| <input type="checkbox"/> Not recommended by health care professional | <input type="checkbox"/> Not aware of risk for illnesses related to treatments |
| <input type="checkbox"/> Uninformed about preventative care | <input type="checkbox"/> Not discussed with health care professional |
| <input type="checkbox"/> Lack of education and/or low literacy level | <input type="checkbox"/> Myths and false information |
| <input type="checkbox"/> Not aware of programs in the community | <input type="checkbox"/> Not aware of risk for secondary cancer |

Other (please specify) _____

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

E. Obstacles and Barriers to Care (cont...)

12. Which of the following are obstacles and barriers to breast cancer survivorship in regards to CULTURAL AND BEHAVIORAL FACTORS? Please select up to 3.

- | | |
|---|--|
| <input type="checkbox"/> Embarrassment/modesty | <input type="checkbox"/> Distrust of the medical systems |
| <input type="checkbox"/> Other more urgent problems | <input type="checkbox"/> Forget |
| <input type="checkbox"/> Conflict with religious beliefs | <input type="checkbox"/> Spouse/partner does not approve |
| <input type="checkbox"/> Concerns about privacy | <input type="checkbox"/> Lack of family support |
| <input type="checkbox"/> Put off procedure | |
| <input type="checkbox"/> Lack of social support (friends, etc.) | |

Other (please specify) _____

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

F. Treatment Options and Preferences

1. How do most women in the community that you serve pay for breast cancer survivorship services? Please select up to 3.

- | | |
|---|--|
| <input type="checkbox"/> Medicaid or Medicare | <input type="checkbox"/> Unable to pay |
| <input type="checkbox"/> Private insurance | <input type="checkbox"/> Cash or check |
| <input type="checkbox"/> Credit card | <input type="checkbox"/> Loan |
| <input type="checkbox"/> Charities | |

Other (please specify) _____

2. Where do low income or underserved women go for breast cancer survivorship services? Please select up to 3.

- | | |
|--|---|
| <input type="checkbox"/> Nurses or other health professional | <input type="checkbox"/> Non-traditional healer |
| <input type="checkbox"/> Physician office or private clinic | <input type="checkbox"/> County Health Department |
| <input type="checkbox"/> Nurse practitioner/ physician assistant | <input type="checkbox"/> Community or public clinic |
| <input type="checkbox"/> Emergency room or hospital | |

Other (please specify) _____

3. In the community that you serve, who oversees breast cancer survivors' healthcare? Please select all that apply.

- | | |
|--|---|
| <input type="checkbox"/> Multidisciplinary team of oncology clinicians | <input type="checkbox"/> Internist/Primary Care Physician |
| <input type="checkbox"/> Medical oncologist | <input type="checkbox"/> Radiologist |
| <input type="checkbox"/> Nurse | <input type="checkbox"/> Gynecologist |
| <input type="checkbox"/> Surgeon | <input type="checkbox"/> Radiation oncologist |
| <input type="checkbox"/> Nurse practitioner/physician assistant | |

Other (please specify) _____

4. Do you believe that a large number of breast cancer survivors are not getting recommended follow-up care?

- Yes
 No
 Not sure

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

G. Organizations

6. Are BREAST HEALTH AND DIAGNOSTIC SERVICES available in the county/counties that you serve? If NOT, how far away is the closest community?

- Yes
- No
- Not sure

Closest Community:

- <15 miles
- 15-30 miles
- 31-60 miles
- 61-100 miles
- >100 miles

7. Where do you send patients for BREAST HEALTH AND DIAGNOSTIC SERVICES?

8. Are BREAST CANCER TREATMENT CENTERS available in the county/counties that you serve? If not, how far away is the closest community where treatment is available?

- Yes
- No
- Not sure

Closest community:

- <15 miles
- 15-30 miles
- 31-60 miles
- 61-100 miles
- >100 miles

9. What are the most visible or active breast cancer survivorship health care programs and/or non-profit organizations in your community?

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

G. Organizations (cont...)

10. What financial resources are available for Breast Cancer Survivorship services?

11. Are there adequate support groups for breast cancer survivors in the community that you serve?

- Yes
- No
- Not sure

12. Are there adequate support groups for FAMILY MEMBERS of breast cancer survivors (including children) in the community that you serve?

- Yes
- No
- Not sure

13. Are there adequate support groups for CAREGIVERS of breast cancer survivors in the community that you serve?

- Yes
- No
- Not sure

14. When are breast cancer survivors referred back to their primary care physician for health care and cancer surveillance?

- Immediately following primary treatment
- Less than 2 years following primary treatment
- 2-5 years following primary treatment
- 6-10 years following primary treatment
- After 10 years
- Cancer specialists follow survivors for life
- I don't know

15. Is there a program that helps breast cancer survivors navigate the medical system in a way that ensures the patient gets needed services?

- Yes
- No
- Not sure

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

G. Organizations (cont...)

16. What types of navigation are provided and who provides them? Please select all that apply.

- | | |
|--|---|
| <input type="checkbox"/> Transportation_____ | <input type="checkbox"/> Prosthesis, wigs and/or bra_____ |
| <input type="checkbox"/> Financial Assistance_____ | <input type="checkbox"/> Medicaid_____ |
| <input type="checkbox"/> Support Services_____ | <input type="checkbox"/> Lymphedema Products_____ |
| <input type="checkbox"/> Not sure | |

Other (please specify)_____

17. What additional support services are offered to breast cancer survivors? Please select all that apply:

- | | |
|--|---|
| <input type="checkbox"/> Exercise and fitness programs | <input type="checkbox"/> Nutrition counseling |
| <input type="checkbox"/> Personal appearance including makeup and wigs | <input type="checkbox"/> Bone health programs |
| <input type="checkbox"/> Massage therapy | <input type="checkbox"/> Lymphedema counseling |
| <input type="checkbox"/> Spirituality programs | <input type="checkbox"/> Fertility counseling |
| <input type="checkbox"/> Psychological counseling | <input type="checkbox"/> Palliative care services/pain symptom management |
| <input type="checkbox"/> Financial counseling | <input type="checkbox"/> Palliative care/end of life services |
| <input type="checkbox"/> Aquatic therapy | <input type="checkbox"/> Relaxation training |
| <input type="checkbox"/> Sexuality programs | <input type="checkbox"/> Heart health programs |
| <input type="checkbox"/> Genetic testing and counseling | |
| <input type="checkbox"/> Prosthesis services | |

Other (please specify)_____

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

G. Organizations (cont...)

18. In your opinion, how important are the following survivorship services in the care of breast cancer survivors?

	Not at all important	Not very important	Somewhat important	Important	Very important
s) Heart health programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) Sexuality programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u) Relaxation training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) Prosthesis services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w) Financial counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) Massage therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y) Psychological counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
z) Exercise and fitness programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
aa) Palliative care services/ pain symptom management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
bb) Palliative care/end of life services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
cc) Fertility counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
dd) Personal appearance including makeup and wigs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ee) Aquatic therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ff) Lymphedema counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
gg) Genetic testing and counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hh) Bone health programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii) Nutrition counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
jj) Spirituality programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

G. Organizations (cont...)

19. In the community you serve, which of the following PRACTICAL PROBLEMS have the greatest need for support in regards to breast cancer survivors? Please select up to 3.

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

20. In the community you serve, which of the following FAMILY PROBLEMS have the greatest need for support in regards to breast cancer survivors? Please select up to 3.

- Dealing with children
- Dealing with partner
- Ability to have children
- Family health issues

21. In the community you serve, which of the following EMOTIONAL PROBLEMS have the greatest need for support in regards to breast cancer survivors? Please select up to 3.

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities
- Spiritual/religious concerns

22. In the community you serve, which of the following PHYSICAL PROBLEMS have the greatest need for support in regards to breast cancer survivors? Please select up to 5.

- | | |
|---|---|
| <input type="checkbox"/> Appearance | <input type="checkbox"/> Indigestion |
| <input type="checkbox"/> Bathing/dressing | <input type="checkbox"/> Memory/concentration |
| <input type="checkbox"/> Breathing | <input type="checkbox"/> Mouth sores |
| <input type="checkbox"/> Changes in urination | <input type="checkbox"/> Nausea |
| <input type="checkbox"/> Constipation | <input type="checkbox"/> Nose dry/congested |
| <input type="checkbox"/> Diarrhea | <input type="checkbox"/> Pain |
| <input type="checkbox"/> Eating | <input type="checkbox"/> Sexual |
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Skin dry/itchy |
| <input type="checkbox"/> Feeling swollen | <input type="checkbox"/> Sleep |
| <input type="checkbox"/> Fevers | <input type="checkbox"/> Substance abuse |
| <input type="checkbox"/> Getting around | <input type="checkbox"/> Tingling in hands/feet |

Appendix A: Surveys

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Healthcare Professional Survey

H. Conclusion (cont...)

If you are willing to participate in a one-on-one telephone interview scheduled at your convenience:

- Please fill out and submit the provided, separate contact information form by **March 31, 2015**
- Mail CONTACT information form with the envelope provided, by **March 31, 2015** to:

Rebecca Di Piazza
Breast Cancer Survivorship Rehabilitation Initiative
St. Vincent's Foundation of Alabama, Inc.
1 Medical Park East Drive
Birmingham, AL 35235

- Mail completed SURVEY with the envelope provided, by **March 31, 2015** to:

Alia Tunagur
Breast Cancer Survivorship Rehabilitation Initiative
St. Vincent's Foundation of Alabama, Inc.
1 Medical Park East Drive
Birmingham, AL 35235

Appendix B: Interview Questions

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survey Follow-up

Interview Questions

- 1) What do breast cancer survivorship services mean to you?
- 2) Where are the gaps in breast cancer survivorship services for women in your community?
- 3) What would improve the present breast cancer survivorship services offered in your community?
- 4) What do you think are the most important health and breast cancer survivorship issues to advocate for?
- 5) What would be your recommendations in developing an effective program for breast cancer survivorship rehabilitation? (Think outside the box, what would have made things better if you could have had ANYTHING?)
- 6) Expound on what can be done to reduce barriers/obstacles to breast cancer survivorship care.
- 7) What support groups are available to breast cancer survivors and their families/caregivers? Is it a general support group or a group specific to breast cancer?
- 8) If a breast cancer survivorship rehabilitation program existed in the Greater Birmingham area, would you refer patients to, and or/use it?
- 9) If you could have your dream (program), what would it be/entail?
- 10) Would you be willing to participate in a focus group?

Appendix C: Discussion Groups

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survey Follow-up

Survivor Discussion Group Guide

Welcome and Introduction:

Hi Ladies! Welcome to this focus group session. My name is **Rebecca Di Piazza**. I am **the Project Director for the Breast Cancer Survivorship Rehabilitation Initiative**. My role in _____ focus group is to facilitate the discussion.

Attending with me today is Alia Tunagur. Alia is the Data Analyst for BCSRI. Alia's role _____ will be to take notes and help document your answers.

The purpose of today's focus group is to **discuss breast cancer survivors' needs following treatment through the balance of life. Survivorship needs can include Clinical/Medical needs (such as physical therapy, genetic testing, or cardiology , Integrative Therapy (such as diet, exercise, weight management, acupuncture, yoga, and massage), and Psychosocial needs (such as Sleep Disorders, Fatigue, Cognitive Impairment, Counseling, Support Groups, and Wellness)**. The information provided by you today will assist in the development of a **community-based, patient-centered comprehensive program to assist survivors and their families that have faced a breast cancer diagnosis**. _____ focus group is estimated to last until _____.

Your participation in this discussion is strictly voluntary and all responses will be anonymous when the information is presented. You may choose to withdraw from the discussion at any time. However, your collaboration is very important for the success of the development of this program. In addition, all information will be kept confidential and anonymous in the final report.

Because we want to accurately remember your ideas and thoughts, we will be voice recording this discussion. We are recording this session simply because we cannot write as fast as you talk. The recording will be transcribed for a written report for all the Health Systems in the Greater Birmingham area and the community as a whole.

We encourage you to participate actively and share your ideas freely. We truly appreciate your attendance and participation! Does anyone have any questions about the focus group?

[Moderator: Pause for a brief moment and answer any questions that the participants may have]

At this time, we kindly ask that if you chose to participate in _____ focus group, to please complete the "Focus Group Participant Consent Form."

[Moderator: Pause and allow time for participants to complete consent form and demographic form.]

Appendix C: Discussion Groups

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survey Follow-up Survivor Discussion Group Guide (cont...)

Ground Rules for Group Interaction:

To begin, let me lay down some basic ground rules:

1. There are no “right” or wrong answers. Any responses that you share are valuable
2. We invite your participation and value your input throughout today's/tonight's session. However please know that we respect your option to choose not to speak on certain topics/questions. Your relationship with the Breast Cancer Survivorship Rehabilitation Initiative is in no way linked to your level of participation.
3. Likewise, there are no rewards for higher levels of participation.
4. You do not have to answer every question. For those of you who wish to respond, please respond as completely and accurately as possible.
5. We ask that only one person talk at a time so that all comments can be acknowledged and noted accurately.
6. In addition, please listen to each other and feel free to agree or disagree in a respectful manner.
7. As moderator, I do receive the right to end a discussion or move the discussion along in the interest of time.

Ice Breaker:

Let's begin by introducing ourselves by first name only and **(insert ice breaker question)**.

Examples of ice breaker questions:

- What is one activity that you enjoyed doing this past Summer?
- What is one of your favorite things about Spring?
- 1 or 2 things you'd like to share with us about yourself (e.g. where you are from, your occupation family, etc.)
- What is one thing you are looking forward to in the near future?
- How has your experience with breast cancer shaped how you look at the future?
- What is your favorite season and why?
- What particular sport do you enjoy?

[Moderator: Go around the room and let each participant introduce themselves and answer the icebreaker question or have them introduce themselves to the person on their right and say two things they should know about them. Then have them introduce each other to the group and say two things about them.]

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survey Follow-up

Survivor Discussion Group Guide (cont...)

Begin Focus Group Questions:

- 1) **What survivorship services were provided? What was offered? Where was it offered? Did you take advantage of the services offered? Were the services personalized?**
- 2) **What did your doctors tell you to do to get well after treatment?**
- 3) **Tell me about your experience with breast health providers? Did you experience any barriers/problems with follow-up care?**
- 4) **What information, support, or resources have been lacking during your survivorship years?**
- 5) **What type of survivorship activities would you like to see in our community?**
- 6) **If you could have your dream Survivorship Program, what would it be/entail?**
- 7) **What do you do different now than you did before your diagnosis? Why?**
- 8) **How has your breast cancer diagnosis affected your life- physical, financially, and emotionally?**

Conclusion:

Before we close, is there anything else that anyone would want to add to our discussion?

Thank you very much for your participation. We truly appreciate the time that you have invested in assisting the **BCSRI**.

Appendix C: Discussion Groups

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survey Follow-up

Healthcare Professional Discussion Group Guide

Welcome and Introduction:

Hi Ladies! Welcome to this discussion group session. My name is **Rebecca Di Piazza**. I am **the Project Director for the Breast Cancer Survivorship Rehabilitation Initiative**. My role in _____ focus group is to facilitate the discussion.

Attending with me tonight is Alia Tunagur. Alia is the Data Analyst for BCSRI. Alia's role _____ will be to take notes and help document your answers.

The purpose of tonight's focus group is to **discuss breast cancer survivors' needs following treatment through the balance of life. Survivorship needs can include Clinical/Medical needs (such as physical therapy, genetic testing, or cardiology), Integrative Therapy (such as diet, exercise, weight management, acupuncture, yoga, and massage), and Psychosocial needs (such as Sleep Disorders, Fatigue, Cognitive Impairment, Counseling, Support Groups, and Wellness)**. The information provided by you tonight will assist in the development of a **community-based, patient-centered comprehensive program to assist survivors and their families that have faced a breast cancer diagnosis**. _____ focus group is estimated to last until _____.

Your participation in this discussion is strictly voluntary and all responses will be anonymous when the information is presented. You may choose to withdraw from the discussion at any time. However, your collaboration is very important for the success of the development of this program. In addition, all information will be kept confidential and anonymous in the final report.

Because we want to accurately remember your ideas and thoughts, we will be voice recording this discussion. We are recording this session simply because we cannot write as fast as you talk. The recording will be transcribed and anonymous excerpts may be included in a written report for all the Health Systems in the Greater Birmingham area and the community as a whole.

We encourage you to participate actively and share your ideas freely. We truly appreciate your attendance and participation! Does anyone have any questions about the focus group?

[Moderator: Pause for a brief moment and answer any questions that the participants may have]

At this time, we kindly ask that if you chose to participate in _____ focus group, to please complete the "Focus Group Participant Consent Form."

[Moderator: Pause and allow time for participants to complete consent form and demographic form.]

Appendix C: Discussion Groups

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survey Follow-up

Healthcare Professional Discussion Group Guide (cont...)

Ground Rules for Group Interaction:

To begin, let me lay down some basic ground rules:

1. There are no “right” or wrong answers. Any responses that you share are valuable.
2. We invite your participation and value your input throughout tonight’s session. However please know that we respect your option to choose not to speak on certain topics/questions. Your relationship with the Breast Cancer Survivorship Rehabilitation Initiative is in no way linked to your level of participation.
3. Likewise, there are no rewards for higher levels of participation.
4. You do not have to answer every question. For those of you who wish to respond, please respond as completely and accurately as possible.
5. We ask that only one person talk at a time so that all comments can be acknowledged and noted accurately.
6. In addition, please listen to each other and feel free to agree or disagree in a respectful manner.
7. As moderator, I do reserve the right to end a discussion or move the discussion along in the interest of time.

Ice Breaker:

Let’s begin with a quick ice breaker! Let’s introduce ourselves by first name only and tell us... **(insert ice breaker question)**.

Examples of ice breaker questions:

- What is one activity that you enjoyed doing this past Summer?
- What is one of your favorite things about Spring?
- 1 or 2 things you’d like to share with us about yourself (e.g. where you are from, your occupation family, etc.)
- What is one thing you are looking forward to in the near future?
- How has your experience with breast cancer shaped how you look at the future?
- What is your favorite season and why?
- What particular sport do you enjoy?

[Moderator: Go around the room and let each participant introduce themselves and answer the icebreaker question or have them introduce themselves to the person on their right and say two things they should know about them. Then have them introduce each other to the group and say two things about them.]

Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) Survey Follow-up

Healthcare Professional Discussion Group Guide (cont...)

Begin Focus Group Questions:

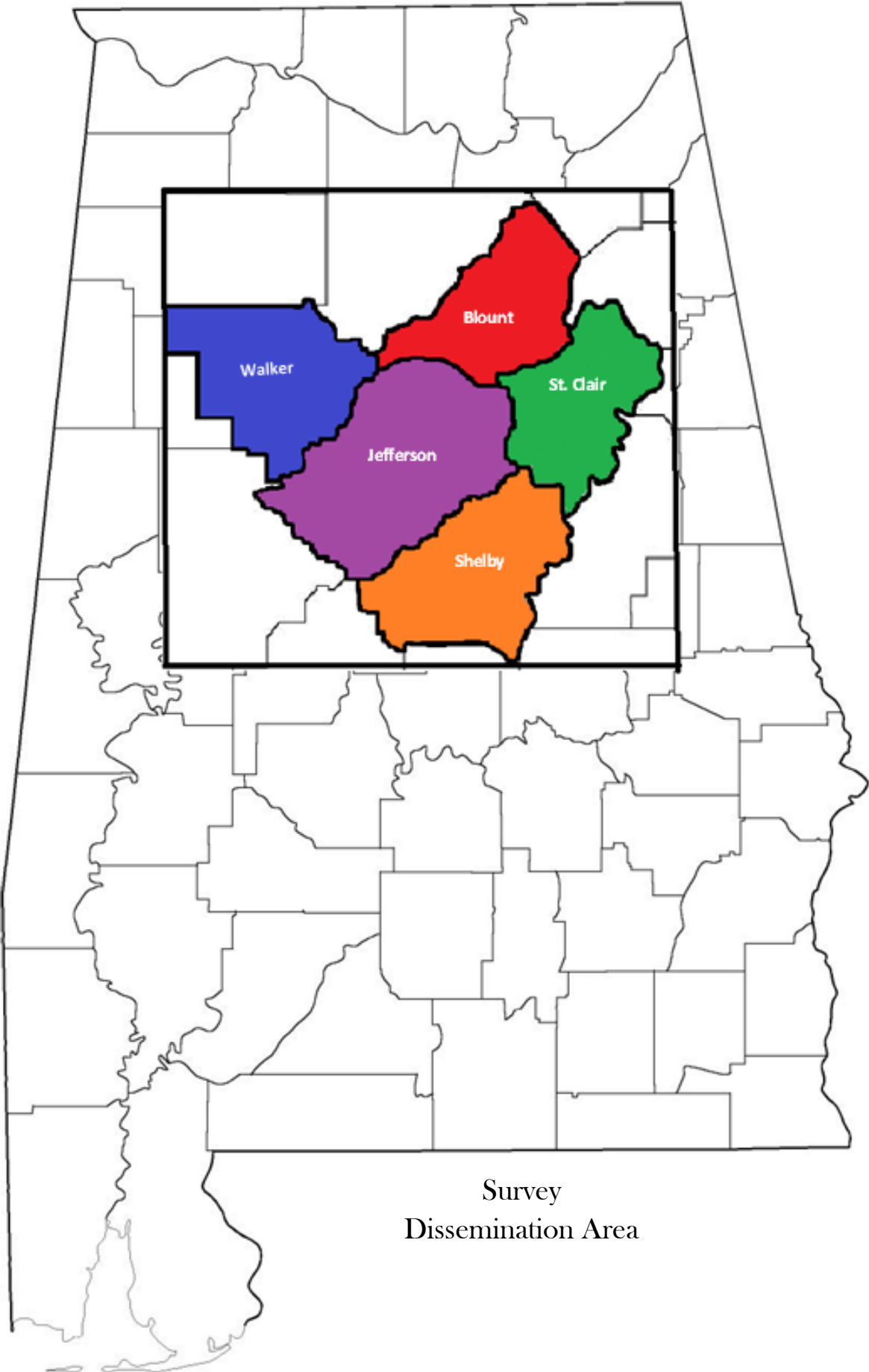
- 1) What does the term “breast cancer survivorship services” mean to you?
- 2) What kind of after care or follow-up treatment is offered by your organization?
- 3) Does your organization offer support services following treatment?
- 4) If aftercare is not provided, who refers patients to other resources? Where are they referred?
- 5) What are the barriers or gaps you face in delivering survivorship services to your patients?
- 6) What are the barriers and gaps your patients face in order to access services?
- 7) What would your dream program look like?
- 8) What do patients need in this program?

Conclusion:

Before we close, is there anything else that anyone would want to add to our discussion?

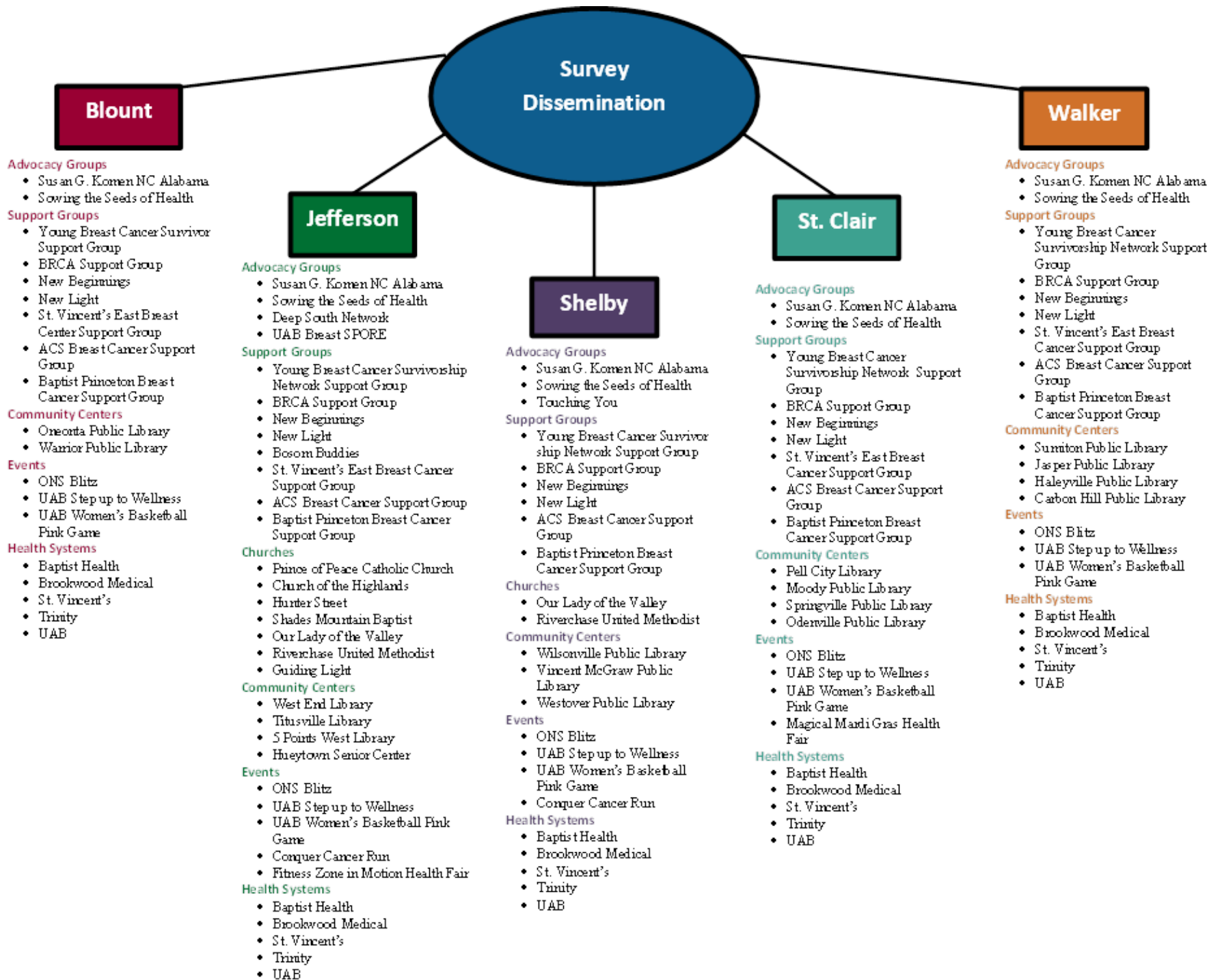
Thank you very much for your participation. We truly appreciate the time that you have invested in assisting the **BCSRI**.

Appendix D: Survey Dissemination Strategy



Survey
Dissemination Area

Appendix D: Survey Dissemination Strategy



Appendix E: Survivorship Programs

The Breast Cancer Survivorship Initiative (BCSRI) conducted interviews with Directors of 12 Survivorship Programs throughout the country including:

- 1. You can Thrive!**
- 2. Memorial Sloan Kettering Cancer Survivorship Center**
- 3. TurningPoint Breast Cancer Rehabilitation**
- 4. Dana Farber Adult Survivorship Program**
- 5. Fred Hutchinson Survivorship Clinic**
- 6. Gilda's Club Nashville**
- 7. U Penn Abramson Cancer Center: Living Well After Cancer Program**
- 8. UCLA Survivorship Center of Excellence**
- 9. University of North Carolina: Carolina Well Survivorship Program**
- 10. City of Hope**
- 11. Vanderbilt University: REACH for Cancer Survivorship**
- 12. Johns Hopkins: Breast Cancer Survivorship Care**