

Recruiting Young Breast Cancer Survivors and High-Risk Relatives to a Randomized Trial using a State Cancer Registry

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Special Interest Project (SIP11-044)

Potential for Cancer Screening Interventions for Cancer Survivors Delivered Through Central Cancer Registries

- Prevention Research Centers (PRC) Program's Special Interest Project (SIP)
- Aims:
 - Identify and contact cancer survivors at increased risk of breast or colorectal cancer using central cancer registry
 - Women diagnosed with breast cancer at 25-45 years (YBCS)
 - Men and women diagnosed with colorectal cancer at <50 years
 - Identify and contact family members of cancer survivors (with permission from the cancer survivor) who may be at increased risk of breast or colorectal cancer based on the cancer survivors tumor, age at diagnosis, or family history
- Three year project awarded to three Prevention Research Center grantees in 2011
 - All three grantees focused on breast cancer survivors and relatives

High Risk Groups for Breast Cancer

- **Risk for a breast cancer survivor**
 - 2-fold higher risk compared to women without breast cancer
- **Breast Cancer Risk for YBCS Relatives**
 - Risks to be further defined by Gail and Claus
 - First-degree relative (i.e. mother, sister, daughter)
 - 2.3 relative risk
 - Second-degree relative (i.e. aunt, grandchild, grandmother, half-sister, etc.)
 - 1.5 relative risk

Specific Aims of Michigan's project

- 1. *Identify and survey 3,000 YBCS (diagnosed at 20-45 y.o.)***
 - breast cancer screening utilization
 - perceived barriers and facilitators to screening
- 2. *Identify and survey up to 2 unaffected 1°- and/or 2° female relatives per YBCS***
 - breast cancer screening utilization
 - perceived barriers and facilitators to screening
- 3. *Test the efficacy of two versions (targeted vs. enhanced tailored) of an evidence-based intervention among YBCS and their female relatives***
 - breast cancer screening utilization
 - other outcomes related to screening

Michigan's Aim 1 Procedures and Progress to Date

Specific Aim 1:

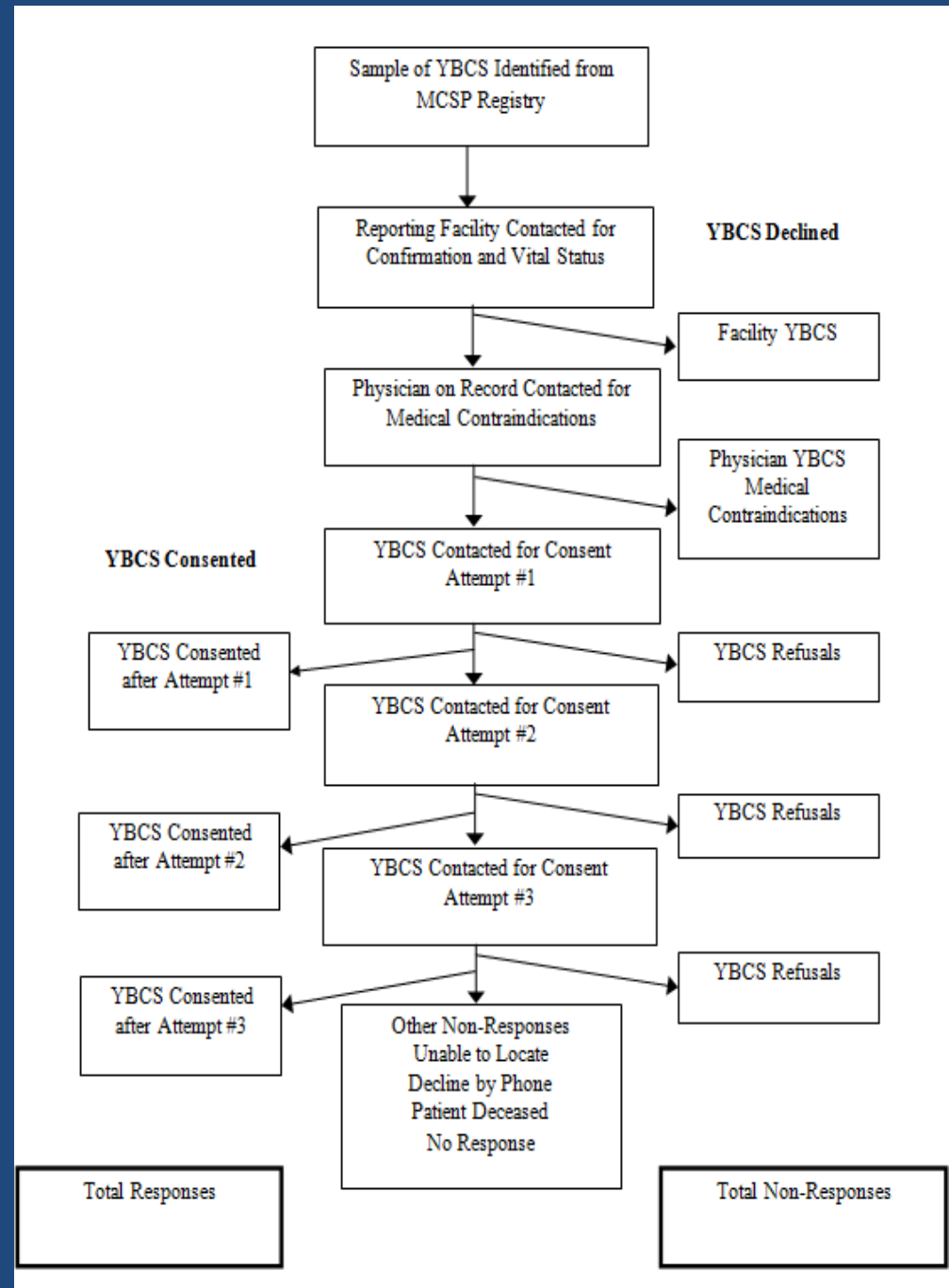
Identify and survey 3,000 YBCS (diagnosed at 20-45 y.o.)

- Michigan Department of Community Health examined Cancer Registry data from breast cancer cases diagnosed in 1994-2008
 - Stratified for counties with high mortality rates of breast cancer diagnosed at young age and for blacks
 - Matched with vital records to exclude deceased
 - Identified 3000 YBCS (50% black; 50% other)

Eligibility Criteria for YBCS:

- Female
- 25-64 years of age
- Being diagnosed with unilateral or bilateral invasive breast cancer between 20 and 45 years of age
- Being diagnosed with DCIS between 20 and 45 years of age
- Michigan resident at time of diagnosis
- Able to read and understand English
- Not currently pregnant, incarcerated, or institutionalized

- ✓ 3000 YBCS identified from 107 facilities
- ✓ All 107 facilities contacted
- ✓ 73 facilities responded with YBCS physician information
 - Awaiting information from 34 facilities
- ✓ To date, 17 originally identified YBCS 'refusals/declined':
 - 13 reported as deceased
 - 1 incarcerated
 - 3 other reasons (mental illness, etc.)
- ✓ 815 YBCS are ready to receive surveys
 - ✓ First batch to be sent out on August 15, 2012
 - 40% response rate expected



YBCS and Relatives Baseline Survey Instrument

- Baseline Mail Survey completed
- 28 pages
 - Demographics
 - Personal and family history of cancer
 - Family Support
 - Genetic counseling/testing
 - Screening behaviors
- Stored in ACCESS database

ID:

CANCER SCREENING IN BREAST CANCER SURVIVORS AND THEIR FEMALE RELATIVES



***University of Michigan and
Michigan Department of Community Health***

Michigan's Aim 2 Procedures

Specific Aim 2:

Identify and survey YBCS' first degree and/or second degree female relatives

- Michigan Department of Community Health (MDCH) board-certified genetic counselors to review baseline surveys of YBCS to identify up to 2 high risk female relatives (1^o and 2^o relative)
- YBCS and relatives to be randomized as a family unit to University of Michigan (UM) or MDCH 'Project Navigators'
- YBCS receives materials to recruit up to 2 relatives identified by MDCH
 - 604 completed surveys expected to be returned by YBCS relatives
- MDCH to identify if hereditary cancer syndrome known for YBCS or relatives
 - Exclude from Aim 3
 - MDCH board-certified genetic counselor to follow-up with each of these families

Eligibility Criteria for High-Risk Female Relatives:


- Female
- First- or second- degree relatives of YBCS
- 25-64 years of age
- US resident
- Able to read and understand English
- Unaffected with any type of cancer
- Not currently pregnant, incarcerated, or institutionalized
- YBCS is willing to contact

Michigan's Aim 3 Procedures

Specific Aim 3:

Test the efficacy of two versions (targeted vs. enhanced tailored) intervention among YBCS and relatives

- Family randomized as a unit
- Personalized letter
 - Enhanced tailored letter based on responses to baseline survey
 - Relatives in enhanced tailored version to receive Gail/Claus scores
- Intervention include brochure(s)
 - Enhanced tailored receive additional brochure on family communication and support
- Follow-up survey to be created and sent to YBCS and relatives ~9 months after intervention



**Breast Cancer Screening
for You and Your Family**

**A Guide For Young Breast Cancer Survivors and
Their Female Relatives**

University of Michigan
M School of Nursing

For more information visit
www.migeneticsconnection.org,
call 1-866-852-1247 or
email genetics@michigan.gov

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Breast Cancer and Your Family: How to Improve Communication and Support

A guide for survivors and their family members

Breast cancer treatments and follow-up care can be stressful for women and their families.

Talking with your relatives about your family's risk for breast cancer also can be very hard to do.

Open family communication can help both survivors and their relatives deal with this stress. It can help you support each other and bring your family closer. It can also help you work as a team to lower your cancer risk.

This brochure has practical and useful tips on

- how to talk to your relatives about cancer risk
- how to find ways to support each other



**Reach out to each other for support because
"A shared burden is half a burden."**

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