

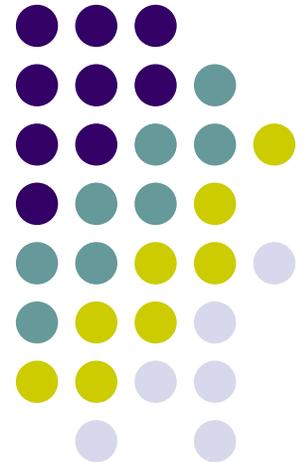
*PHASE Intern Report:*

# Development of a Survey to Assess Disparities in Breast Cancer Care on the Eastern Shore of Maryland

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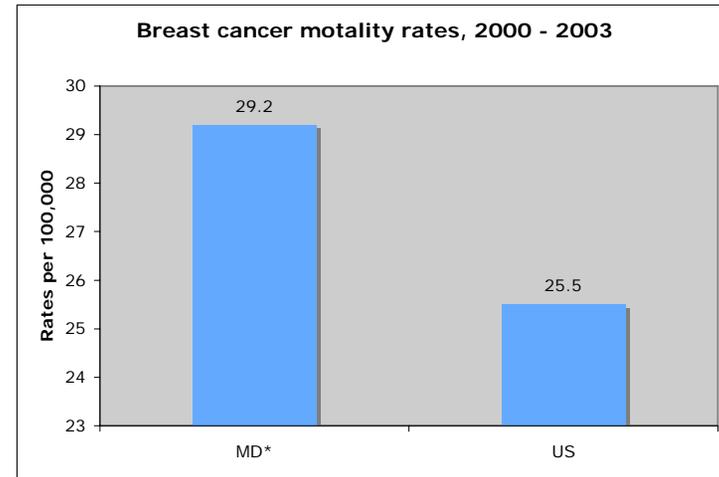
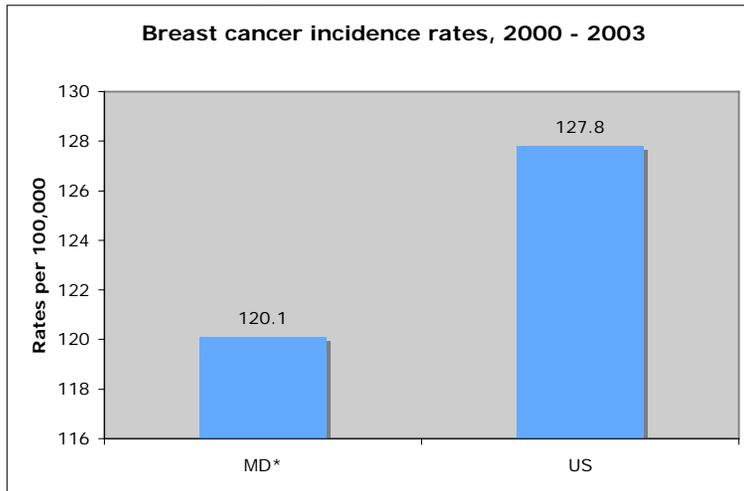
MPH advisor: Yin Yao





# Background

- Breast cancer is the most commonly diagnosed cancer among women in the US and the state of MD



\*MD rates from 2002    \*\* SEER, 2000 - 2003

- Despite the improvement in outcome of breast cancer over decades, disparities in breast cancer care exists



# Barriers to quality breast cancer care

MD DHMH identified following contributing factors to cancer disparities

Patient  
level

Risk factors and exposures  
Socioeconomic status  
Discrimination  
Attitudes and behaviors  
Access to quality care  
Delay in seeking diagnosis and treatment  
Culture and language

Provider/  
Systems  
level

Social, economic, and public health environment  
: Race/ethnicity, socioeconomic status, poverty, education, age, language, geography

# Eastern Shore and Worcester County



- The largest rural region in MD
- High proportion of population over 50
- Rapid increase in population due to in-migration of retirees
- Designated “medically underserved area” by HRSA since 1978
- Most common cause of death: cancer



# Comprehensive Cancer Control Plans by CDC

- “an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention (primary prevention), early detection (secondary prevention), treatment, rehabilitation, and palliation.”
  - 1) Enhancing infrastructure
  - 2) Mobilizing support
  - 3) *Using data and research*
  - 4) *Building partnership*
  - 5) Assess and address cancer burden
  - 6) Conduct evaluation

# Data and research



- Existing sources of data
  - Local Health Plan
  - Tri-County Community Adult Health Survey
  - MD Cancer Registry
- Limitations
  - Not sufficient for assessing cancer burden or identifying service needs
  - Small number of cases
  - Lack of individual socioeconomic data
  - Uneven quality of data from smaller populations

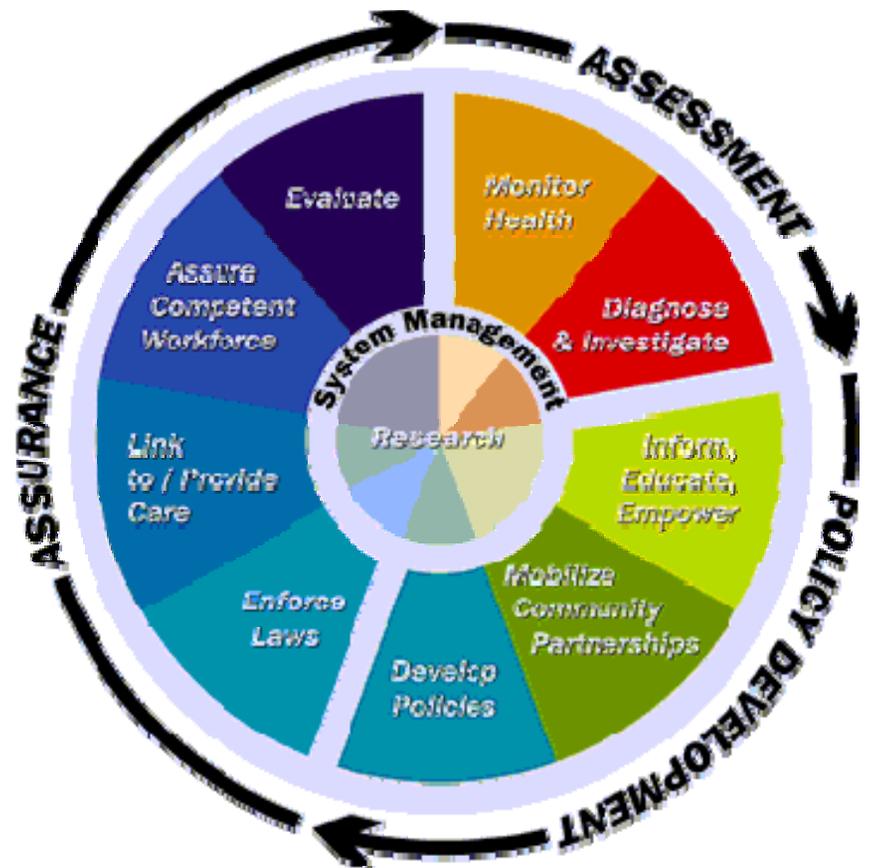
# Community partnership



- Worcester County Cancer Coalition Meetings
  - Primary prevention and early detection of cancer in Worcester county
  - Smoking cessation programs, recruiting community members to BCCP, community education
  - Members include..
    - Local health department officials
    - ACS liaison
    - Community-based organizations
    - Local hospital representatives

# Project goal

- Mobilize a community partnership in developing survey to establish public health data that can be used to assess the cancer burden in the area



\*Source: Public Health Functions Steering Committee

# More about the partnership...



- Worcester County Health Department
  - Linkage between the PHASE program and the community-based organization
  - Structural meetings and resources
- Women Supporting Women
  - Local breast cancer support group
  - Serves over 1000 breast cancer survivors in the Eastern Shore
  - Links to the mailing list of breast cancer survivors
  - Further distribution and collection of the surveys
- PHASE intern

# Developing the survey content



- Intended to collect comprehensive information along the breast cancer care continuum from screening to diagnosis, treatment, and post-treatment care and support, at both individual and systematic levels
- Initial template: the intake form previously used by WSW to collect basic demographic and clinical data
- Specific question and answer formats from various existing surveys
  - National Action Plan on Breast Cancer, Comprehensive Questionnaire
  - Health Information National Trends Survey
  - US Census categories for income and education categories



# Contents of the survey

- Part I. Use of the support group resources and potential supporting group needs

Q1. What services have you used that were provided by Women Supporting Women? (Check all that apply)			
<input type="radio"/> Support group meetings	<input type="radio"/> Wigs/ hats		
<input type="radio"/> Information totes	<input type="radio"/> Other:		
<input type="radio"/> Cards			
<input type="radio"/> Phone calls			
<input type="radio"/> Piglet pillows			
Q2. What other assistance would you like?			



- Part II. Tumor characteristics and treatment received
  - Timing of screening, diagnosis, and initial treatment
  - Method of tumor detection
  - Tumor characteristics: stage, recurrence, hormone receptors, genetic tests
  - Types of treatment received
  - Distance and method of transportation to the treatment facility

Q3. When were you first diagnosed with breast cancer? \_\_\_/\_\_\_/\_\_\_\_ (mm/dd/yyyy)

Q4. How was your breast cancer found?  
 Mammography  
- When were you found to have abnormal mammogram results? \_\_\_/\_\_\_/\_\_\_\_ (mm/dd/yyyy)  
 Clinical examination (by physician or nurse practitioner)  
 Self breast exam  
 Other: \_\_\_\_\_

Q5. Have you had previous mammograms?  Yes - For how many years? \_\_\_  No

Q6. Have you been diagnosed with breast cancer more than once?  
 No  
 Yes  
- Where was the location of the recurrence?  
 the same breast  the other side  Other \_\_\_\_\_

Q7. What was type of your cancer?  
 Invasive (or infiltrating)  
 Carcinoma in situ (e.g., DCIS, LCIS) ⇒ *Skip to Q9*  
 Other (e.g., Paget's, inflammatory, etc.): \_\_\_\_\_

Q8. If you answered *Noninvasive* or *Other* how spread was your tumor when you were first diagnosed?  
 Local (within the breast)  
 Regional (spread to lymph nodes, but not to distant organs)  
- How many lymph nodes were removed? \_\_\_\_  
- How many of them were positive? \_\_\_\_  
 Distant (metastasized to different areas, such as bone or brain, etc.)  
 Unstaged or don't know

Q9. Did you test positive for any of hormone receptors?  
 Estrogen receptor (ER) -  Yes  No  
 Progesterone receptor (PR) -  Yes  No  
 HER-2 positive -  Yes  No  
 Don't know

Q10. Have you had genetic testing?  
 Yes - Results: \_\_\_\_\_  
 No

Q11. Have you been treated for your breast cancer?  Yes  No

Q12. What was the type of your initial treatment? (Select only one.)  
 Chemotherapy  
 Surgery  
 Radiation  
 Other: \_\_\_\_\_

Q13. When did you first receive that treatment? \_\_\_/\_\_\_/\_\_\_\_ (mm/dd/yyyy)

Q14. What other types of treatment have you received? (Select all that apply)  
 Chemotherapy: (Please describe) \_\_\_\_\_  
- Did you have any problems following chemotherapy?  
 Yes: \_\_\_\_\_  
 No  
 Surgery: (Please describe) \_\_\_\_\_  
- Did you have any problems following the surgery?  
 Yes: \_\_\_\_\_  
 No  
 Reconstruction: (Please describe) \_\_\_\_\_  
- Did you have any problems following the reconstruction?  
 Yes: \_\_\_\_\_  
 No  
 Radiation: (Please describe) \_\_\_\_\_  
- Did you have any problems following the treatment?



- Part III. Individual demographics and socioeconomic status

- Age at diagnosis
- Race/ethnicity
- Marital status
- Language
- Area of residence
- Employment status
- Income
- Education
- Insurance status
- Family history

Q22. What is your date of birth? \_\_\_/\_\_\_/\_\_\_ (mm/yyyy)

Q23. What is your gender?  
 Female  Male

Q24. Which one of these groups would you say best represents your race?  
 White  
 Black or African American  
 Asian  
 Native Hawaiian or Other Pacific Islander  
 American Indian or Alaska Native  
 Other [specify] \_\_\_\_\_

Q25. What is your marital status?  
 Married  Divorced  
 Living together with a partner  Separated  
 Widowed  Single (never married)

Q26. Do you speak a language other than English at home?  
 No  
 Yes: (what language) \_\_\_\_\_  
- If you speak other language at home, how well do you speak English?  
 Very well  Well  Not well  Not at all  
- Would you like to have an interpreter assist you for hospital visits?  
 Yes  No

Q27. What is the zip code of your current address?  
1. How long have you lived in this address? \_\_\_/\_\_\_/\_\_\_ (mm/yr)

Q28. What is the zip code of your last address?  
2. How long have you lived in this address? \_\_\_/\_\_\_/\_\_\_ (mm/yr)

Q29. Are you currently employed?  
 Employed for wages  A homemaker  
 Self-employed  Student  
 Out of work for more than 1 year  Retired  
 Out of work for less than 1 year  Unable to work

Q30. What is your annual household income from all sources?  
 Less than \$10,000  \$35,000 \$ \$49,999  
 \$10,000 \$ \$14,999  \$50,000 \$ \$74,999  
 \$15,000 \$ \$19,999  \$75,000 \$ \$99,999  
 \$20,000 \$ \$24,999  \$100,000 \$ \$199,999  
 \$25,000 \$ \$34,999  \$200,000 or more

Q31. What is the highest grade or year of school you completed?  
 Never attended school or only attended kindergarten  
 Grades 1 through 8 (Elementary)  
 Grades 9 through 11 (Some high school)  
 Grade 12 or GED (High school graduate)  
 College 1 year to 3 years (Some college or technical school)  
 College 4 years or more (College graduate)

Q32. Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?  
 Yes: Please specify.  
 Employment-based Private Insurance  
 Direct-purchase Private Insurance  
 Medicare  
 Medicaid  
 Military Health Care  
 No coverage

Q33. During the past 12 months, not counting times you went to an emergency room or for cancer treatment, how many times did you go to a doctor, nurse or other health care provider to get care for yourself?



# Pilot study with 19 survivors

- 19 WSW members who attended the support group meetings in Berlin or Salisbury
- Revision of answer categories and sub-questions

## DEMOGRAPHICS

<b>Race, No. (%)</b>	
White	19 (100)
<b>Median age (years)</b>	
	63
<b>Age at diagnosis, No. (%)</b>	
less than 50	9 (47.4)
50 Š 59	2 (10.5)
60 Š 69	5 (26.3)
older than 70	2 (10.5)
<b>Marital Status, No. (%)*</b>	
Married	14 (73.7)
Widowed	3 (15.8)
Other	2 (10.5)
<b>Current zip code, No. (%)*</b>	
21811	13 (68.4)
Others	6 (31.6)
<b>Income, No. (%)*</b>	
20000 Š 34999	3 (15.8)
35000 Š 75000	5 (26.3)
75000 Š 99999	3 (15.8)
100000 Š 199999	3 (15.8)
No response	
<b>Insurance, No. (%)</b>	
Employment-based private or military	10 (52.6)
Direct private	5 (26.3)
Medicare only	4 (21.1)
<b>Education, No. (%) *</b>	
High school graduate or less	8 (42.1)
Some college	3 (15.8)
College graduate	8 (42.1)

## TUMOR CHARACTERISTICS

<b>Stage at diagnosis, No. (%)</b>	
Invasive	11 (57.9)
Non-invasive	7 (36.8)
<b>Initial treatment, No. (%)</b>	
Surgery	13 (76.5)
Non-surgical treatment	3 (15.8)



# Future plans

- Data collection by WSW during the summer of 2007
- Target population: WSW members in the mailing list who have voluntarily contacted the support group for assistance or information
- Information obtained will be used to assess and address the cancer burden and disparities of the Eastern Shore Area

# Strengths and limitations



- Focused on collecting both clinical data and individual socioeconomic information
- More appropriate in assessing cancer burden and disparities in smaller geographical area
- Self-selected nature of the survey participants
- Self-reported information

# Thank you



- Worcester County Health Department
- Women Supporting Women
- Dr. Yin Yao
- PHASE interns, Dipti and Dr. Ibrahim