THE GW
CANCER INSTITUTE

an urban oncology center

District of Columbia City-Wide Patient Navigation Research Program (DC-PNRP)
NCI U01 CA116937

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CRCHD
Center to Reduce Cancer Health Disparities
PATIENT NAVIGATION PROGRAM (PNP)

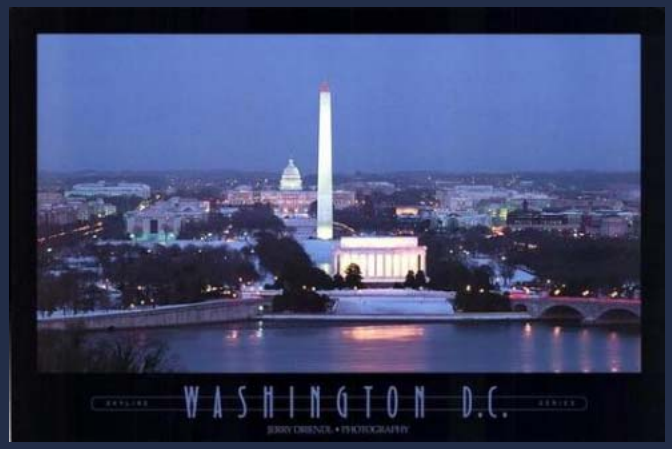
PATIENT NAVIGATION RESEARCH PROGRAM

PATIENT NAVIGATION RESEARCH PROGRAM

GWCI's MISSION

Bringing optimal cancer resources to ALL members of our urban community

- **Dedicated to eliminating cancer disparities in Metropolitan DC**
  - Washington, DC is a microcosm of the national challenge of the *Unequal Burden of Cancer.*



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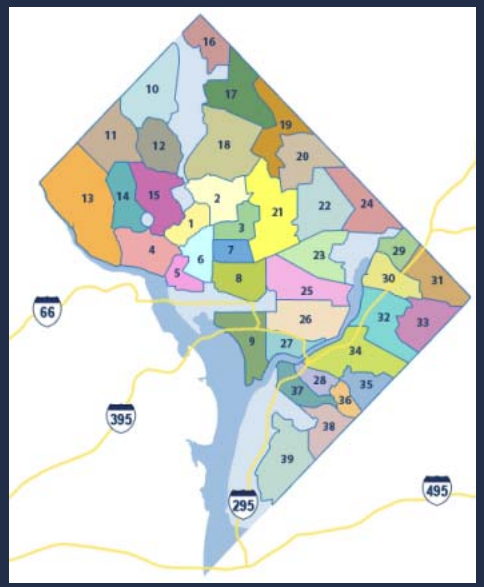
Scope of Our Challenge

- **Small city with big city health challenges (pop 550,000).**
- **High minority population.**
  - 58% Black, 27% non-Hispanic Caucasian, 10% Hispanic



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Framing the Problem: Cancer in DC

- Highest per capita cancer mortality rates in the country
- Approximately 2800 new diagnoses and 1,200 cancer deaths per year
- Cancer is leading cause of death in under 85 population

- Major negative factors:
  - Lack of medical "home" (inadequate primary care
  - Screening difficulties
  - Information Deficit
  - Fragmented health insurance system
    - large % un-insured or underinsured
    - 17% of blacks, 35% of Hispanics are uninsured
  - Poverty
  - Fear and medical mistrust
  - Cultural barriers
  - Health care labyrinth

Framing the Problem: Breast Cancer in DC

- **DC-PNRP focused on breast cancer:**
  - Large magnitude of disparities associated with breast cancer
  - Infrastructure for studying breast cancer through citywide partnership far more developed than for any other cancer site

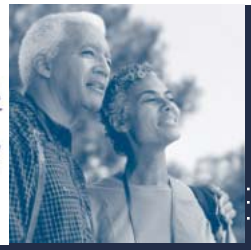
- **OBSERVATIONS:**
  - Approximately 600 DC women diagnosed per year; 120 die
  - Strikes white women more frequently than others, but black women are twice as likely to die
  - Black women & Latinas present at earlier ages, and with more aggressive disease, than whites
  - Often minority women with overt symptoms will not seek medical care

Framing the Problem: Breast Cancer in DC

- **Is there a lack of medical care or screening?** NO
  - 11 hospitals, 4 major medical centers, several networks of community clinics
  - Available evidence suggests that DC collectively exhibits reasonable screening rates

- **Resources not distributed evenly with respect to geography : an entire city quadrant is grossly medically underserved**

  - Mammography screening facilities not available in poverty areas:
    - Total of 19 facilities: 5 not open to public; for 14 remaining, 13 in NW DC and only 1 in SE, but North of the Anacostia River.



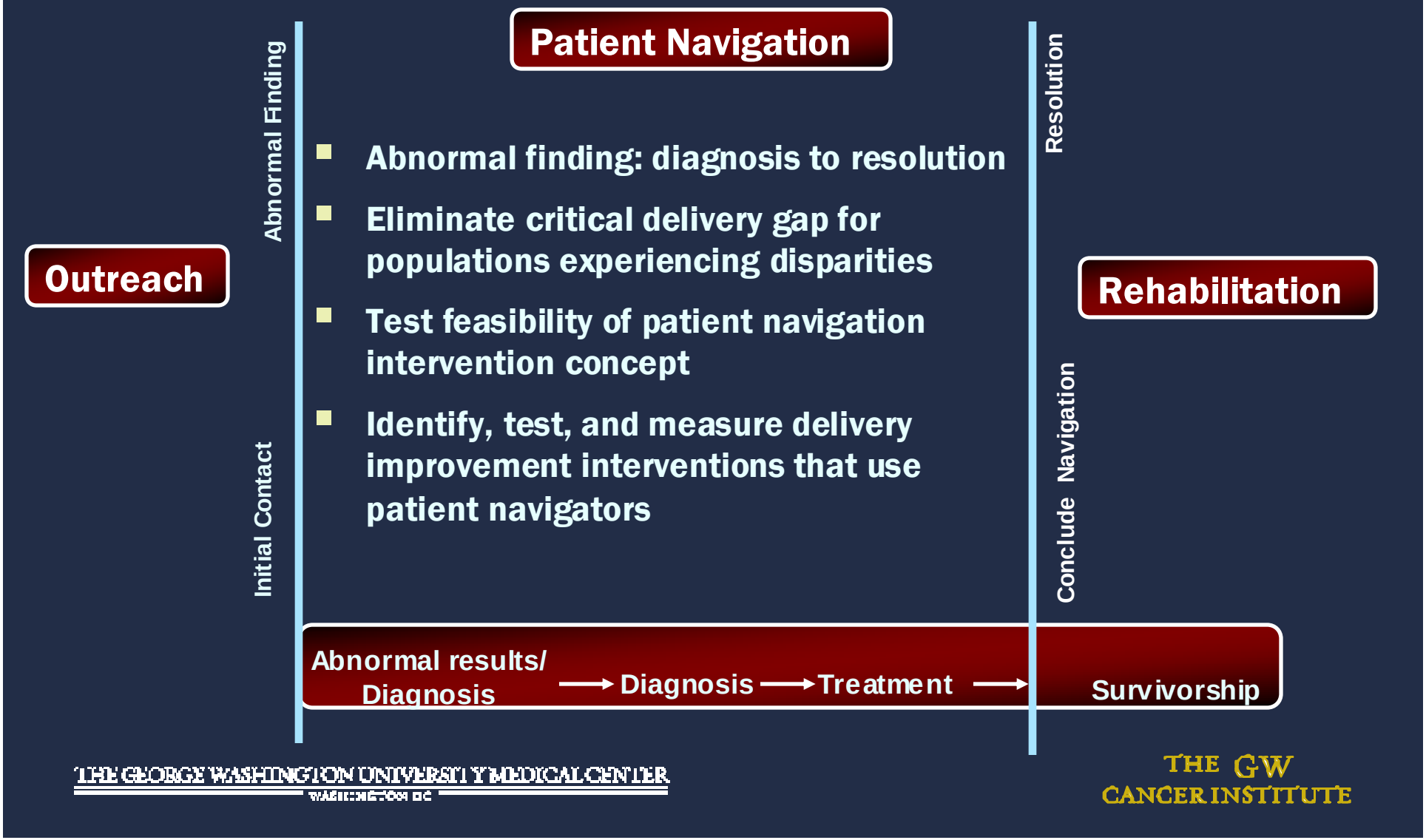
PNRP and Patient Navigation

- **NCI/ACS funded 9 sites as a Cooperative Agreement (U01) across the USA to empirically evaluate effectiveness of patient navigation in reducing cancer mortality**

- **NCI Definition: Patient Navigation provides support and guidance to persons with abnormal findings to help them access timely cancer care and overcome barriers to quality, standard care**

- **Based on the "Harlem" Model Examples of navigator services include:**
  - Arranging financial support
  - Arranging transportation to, and childcare during, scheduled diagnosis and treatment appointments
  - Identifying and scheduling appointments with culturally sensitive caregivers

NCI's General Framework of Patient Navigation Program



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PNRP Global Research Objectives

- **Main hypotheses:**
  - Patient navigation will:
    - **-Reduce and/or eliminate access barriers**
    - **-Improve timeliness and quality of diagnosis and treatment**
    - **-Improve satisfaction with health care system experience**

- **Additional Research Questions:**
  - What is the impact of type of navigator (Social Worker, Nurse, Lay Individual, Community Worker)?
    - Does location of navigator, outpatient or hospital-based, impact outcome?
  - Does the race\ethnicity or language matching of patient and navigator improve outcome?

DC PNRP Original Specific Aims

- **Original Study Design: to Test the Hypotheses that**
  - Enhanced Navigation Plus Standard-Concrete Navigation will be more effective than Standard-Concrete Navigation alone:
    - SCN was defined as overcoming concrete "systems" barriers
    - EN was to include culturally and linguistically matched psychosocial counseling
  - Evaluate Cost Effectiveness in terms of costs per quality-adjusted year of life saved.
    - Analysis will include assessment of factors that mediate the intervention effects (coping styles, perceptions of health care providers, attitudes, fatalism etc).

Success can cause problems!!

- **What happened to "Enhanced Navigation"?**
  - The concept of Patient Navigation has swept the nation making Navigation, and often high level Navigation, routine Standard of Care in many places.
  - GW, WHC and Howard are now routinely offering what we used to call Enhanced Navigation as their Standard of Care (dramatic departure from status in 2004).
  - Lots of navigation "demonstration projects" in DC. Difficult to identify an uncontaminated control.

New DC-PNRP Study Design

- **Consolidated Navigation into one arm**
  - Added a concurrent "DC Usual Care" Control
    - women covered by DC government safety net insurance who do not find their way to one of our sites will serve as "usual care" controls & those who do find their way to one of our RIS will be offered enrollment in intervention arm
  - Additional comparison: historical controls available at 4 sites using hospital tumor registry and medical records

DC-PNRP Hypotheses

Patient navigation will be more effective than current state-of-care in:

- Decreasing time between suspicious finding to diagnostic resolution
- Decreasing time between diagnosis to initiation of treatment
- Cost-effectiveness in terms of costs per quality-adjusted year of life saved

DC-PNRP's Pre-Phase

- **Pre-Phase Activities**
  - Set up Administrative Core
  - Set up Data Management Core
  - Establish an overarching IRB with site specific subs
  - Establish the Program Advisory Group
  - Establish a Community Advisory Panel
  - Conduct self-analysis at each recruitment site
  - Establish National definition of abnormal mammogram
  - Establish National Common Data Elements (CDE)
  - Develop training manuals, checklists, documented procedures, and tracking systems
  - Navigator Training – national and local

- Recruitment Intake Sites (RIS):
  - GW Cancer Institute in affiliation with GW-MFA Breast Care Center (GWCI)
  - Capital Breast Care Center (CBCC; affiliated with Lombardi Cancer Center at Georgetown University)
  - Howard University Cancer Center, Howard University Hospital (HUH)
  - Washington Hospital Center's "Preventorium"
  - Washington Hospital Center's Breast Care Center (on line 9-1-07)
  - Nueva Vida
  - Providence Hospital (on line 9-1-07)
  - DCAHEC at Greater SE Community Hospital

- The Investigators:
  - GW Cancer Institute: Patierno (PI), Paul Levine (Co-I), Lisa Alexander (Co-I), Nancy LaVerda (PM), Heather Young (Data Coordinator), Amnah Taufique (Research Assistant).
    - Capital Breast Care Center: Jeanne Mandelblatt
    - Howard University Cancer Center: Carla Williams
    - WHC Preventorium: Elmer Huerta
    - WHC Breast Care Center: Sandy Swain
    - Nueva Vida: Larisa Caisedo
    - Providence Hospital : William Funderburk
    - DC-AHEC: Kim Bell

The Navigators and Site Coordinators:

- GW MFA Breast Center: Amy Shockley
- Capital Breast Care Center: Tesha Coleman, Ana Nunez, Cheryl Fields, Milajurine Lindsay
- Howard University: Olushola Ode, Kim Higginbotham
- WHC Preventorium: Diana Garcia
- WHC Breast Care Center: Linda Walton
- Nueva Vida: Olga Pulgar-Vidal, Ana Quijada
- Providence Hospital : Gail Smith-Nyachowe

DC-PNRP: Study Status

- **IRB approval received January 2007 for GWU**
  - Followed completion of Common Data Elements by National
  - Other RIS subsequently obtained IRB approvals
- **Two national training events: sponsored by ACS**
- **Local area 2-day training sessions**
- **Monthly meetings: communication, problem solving, sharing resources**
- **Initial data collection began February 2007 for GW site**
- **Enrollment has been low but is now accelerating:**
  - Nearly 70 enrollees
  - Nearly 100 controls (historic)

Challenges

- Difficulty in coordinating such a complex city-wide network.
- Different IRB's with different requirements, expectations and levels of risk avoidance.
- Different SOP's at each site.
- Lower than expected consenting success rate (too many questionnaires, too much time, patients who are too busy, will get the service anyway).
- Many navigation "demonstration projects" being conducted in DC making it difficult to identify an uncontaminated control.
- Defining Navigator "boundries": getting physician buy-in

GWCI's General Framework for Integrated, Seamless Patient Navigation

Patient Navigation

Screening Navigation | **Treatment Navigation** | **Survivorship Navigation**

- **Abnormal finding: diagnosis to resolution**
- **Eliminate critical delivery gap for populations experiencing disparities**
- **Provide seamless transition from screening through treatment and survivorship.**

Outreach

Education

Screening

Initial Contact

Rehabilitation

Palliative Care

Abnormal results/ Diagnosis → Diagnosis → Treatment → Survivorship

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Bringing Screening to the Community

- Another approach: bringing mammography to the community

- GW Mammovan provides about 2500 mammograms/year to medically underserved women in DC, Northern Virginia, & Maryland.
- Program includes a bi-lingual patient navigator
  - With $1.3M in new funding, new state-of-the-art, fully digital Mammovan launched October 2005.

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An urban oncology center dedicated to excellence in cancer care, research, education, and outreach, and to understanding and eliminating cancer disparities.