Aims/Objectives

- Describe the “Disconnect”: disparities in cancer care delivery

- Review Patient Navigation studies: emerging evidence to “repair” the disconnect

- Explore future opportunities: features of health system reform relevant to cancer care
Unequal Burden of Cancer

Despite advances in prevention, screening and treatment for cancer, certain populations continue to show no benefit.

Compared to Whites, racial/ethnic minority and those of low socioeconomic status suffer:
- Higher incidence of many cancers
- More advanced stage at diagnosis, and
- Higher mortality after a cancer diagnosis
Disparities in Breast Cancer

Age Adjusted Incidence and Mortality of Breast Cancer By Race
Breast Cancer Survival by Race/Ethnicity and Insurance

Status; US 1999-2000 diagnosis, ages 18 – 64 years, National Cancer Database.
Factors that Influence Disparity

Screening  Diagnosis  Treatment  Survivorship

*Adapted from IOM 2003
There is a critical *disconnect* between cancer discoveries and cancer care delivery to all patients.
Disparities identified at each step in the evaluation and treatment clinical pathway*: 
- method of detection
- time from first symptoms of cancer to pathologic diagnosis
- time from diagnosis to initiation of treatment

Delays >60 days first treatment for late stage breast cancer affects survival**

*Elmore et al. Med Care 2005
**Paskett et al JCO 2012
Boston Medical Center

- Academic institution serving local community and 15 affiliated community health centers
- Largest safety net institution in New England
  - 747,554 annual visits
  - 70% racial/ethnic minority
  - >50% uninsured or Medicaid
  - 30% non-English speaking

“Exceptional care without exception”
Mammography Adherence in Residency Practice at BMC*

- 515 eligible women 50-69 years
- Only 55% mammogram past 2 years
- No socio-demographic differences
- Non-adherent group less likely have had prior mammogram

*Schroff, Battaglia et al SGIM 2013.
Days to Diagnostic Resolution by Abnormality

NOTE: Dashed line denotes the median number of days by abnormality.

*Battaglia et al Cancer 2010.
Breast Cancer Treatment at BMC

- ER+/PR+ 2006-8
- 36% non-complaint CoC Standard = initiation HT within 365 days of diagnosis
- Non-complaint: non-white, non-US born, later stage at diagnosis
- Multiple reasons contributed to their status
- Longest delays related to social factors and/or complex treatment care plans

*Crowley, Battaglia et al 2012 SGIM Annual conference.*
Patient Navigation:

Emerging evidence to repair the disconnect
Diagnostic Breast Services Model*

- Multi-disciplinary diagnostic practice
  - Primary care
  - Surgical oncology
  - Radiology, Cyto-pathology

- Triage system
  - Low Risk = medical providers
  - High Risk = surgical providers

- Services Provided Concurrently

Needs Assessment (2001)

- High rates late stage disease at BMC
- **36%** referrals never arrived for evaluation

- Key informant interviews
  - Administrative support to facilitate internal and external communication
  - Coordination of patient care, interpreter services
Theoretical Framework

- Patient Navigation (culturally congruent lay health worker) guided by principles of Care Management:
  - Identify Case
  - Identify individual barriers to care
  - Design and implement care plan
  - Long term tracking
Patient Navigation: Diagnostic

- Pre-post intervention design
- Women >18 yrs referred for diagnostic evaluation to breast clinic

**Timely Follow-Up** = arrival to diagnostic appointment within 120 days from the date the original appointment was scheduled
Patient Characteristics
N=1,391

37% White, 38% Black & 14% Hispanic
51% Immigrant
16% Needed Interpreter
67% Public or No Insurance
48% Referred from Community Health Center
**Timely Follow-Up**

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<thead>
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<tr>
<td>Pre-Intervention</td>
<td>64%</td>
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<td>Intervention</td>
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`p <0.0001`

Women in Intervention group had **39%** greater odds of having timely follow-up

Timely Follow-Up

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<tr>
<th>Age Group</th>
<th>Pre-Intervention</th>
<th>Post-Intervention</th>
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<td>18-39</td>
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<td>40-64</td>
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**Significance Levels**

- **AGE**: $P < .001$
- **RACE**: $P = .046$
- **INSURANCE**: $P < .001$
- **INTERPRETER**: $P = .19$
Patient navigation: Screening

- Randomized trial at BMC
- at level of primary care provider

- Women 51-70, no screening mammogram within 18 months

- Outcome: biennial mammogram adherence

Phillips et al. JGIM 2010
Mammography Adherence after 9 Months: Non-navigated (N=2078) vs. Navigated (N=1817)

<table>
<thead>
<tr>
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<th>Nov. 2008</th>
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<td>Non-navigated</td>
<td>77</td>
<td>76.6</td>
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<tr>
<td>Navigated</td>
<td>76</td>
<td>87</td>
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Phillips et al. JGIM 2010
Rapid adoption of the model

- Private Foundations
  - Avon Foundation
  - American Cancer Society
  - Susan G. Komen for the Cure

- Federal Support
  - 2002 NCI funded 6 pilot programs
  - 2005 Patient Navigator Act $25million
  - CMS Demonstration Projects
  - NCI Patient Navigation Research Program
Patient Navigation Research Program
CONCEPTUAL MODEL: Navigation

HEALTH CARE SYSTEM

CLINIC (Type, Size, Providers)

PARTICIPANT CHARACTERISTICS
- Literacy
- Stress/Distress
- Insurance
- Race
- Income
- Co-morbidity
- History
- Education
- Language

EVENT
- (ABNORMAL TEST or SYMPTOM/CANCER)
  - Site (Breast, CRC, Cervical, Prostate)
  - Clinical Characteristics
  - Type of Definitive Test/Treatment Pursued

BARRIER(S)
- Number
- Type
- Intensity

NAVIGATION
- Navigator Characteristics
- Patient Relationships

OUTCOMES
- Time to Resolution
- Time to Treatment Initiation
- Satisfaction/Perceptions
- Costs
- Stress/Distress (IES)

NO NAVIGATION

ACTION(S)
- Number
- Type
- Time
- Intensity
PNRP Main Questions

Will navigated patients…

Receive **timelier, definitive resolution** following an abnormal finding?

Receive **timelier treatments** following a positive diagnosis?

Improve their **satisfaction** with the health care system experience?
PNRP Patient Navigation

- Case identification
- Abnormal screening

- Identify Barriers

- Develop/Implement plan to address barriers

- Tracking

- Tracking

- Resolution

List of 21 pre-defined barriers

List of 10 actions (actions can match each barrier)

Multiple Encounters

Azadeh Nasseh, 2011
PNRP Methods

- Breast, Cervical, Colorectal or Prostate
  - Screening abnormality
  - New cancer diagnosis
- % achieve diagnostic resolution in 365 days
- Prospective Meta-analysis - time to dx
- Pooled Cox Proportional Hazards – time to tx
- Adjusted Hazards Ratio (aHR) > 1.0 indicates more timely care
# PNRP Diagnostic Subjects

N = 10,521

## Demographics

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<tr>
<th></th>
<th>Navigated N=5063</th>
<th>Controls N=5458</th>
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<td><strong>Age (mean)</strong></td>
<td>43.6</td>
<td>47.2</td>
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<td><strong>Race/ethnicity</strong></td>
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<td>Black</td>
<td>29%</td>
<td>34%</td>
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<td>White</td>
<td>24%</td>
<td>25%</td>
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<td>42%</td>
<td>36%</td>
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<tr>
<td><strong>Gender</strong></td>
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<tr>
<td>Female</td>
<td>92%</td>
<td>92%</td>
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<td><strong>Insurance Status</strong></td>
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<tr>
<td>Uninsured</td>
<td>36%</td>
<td>28%</td>
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<tr>
<td>Public</td>
<td>39%</td>
<td>42%</td>
</tr>
<tr>
<td>Private</td>
<td>24%</td>
<td>29%</td>
</tr>
</tbody>
</table>
% Who Complete Diagnostic Evaluation By Type of Cancer Screen and PNRP Program

Breast | Cervical | Colorectal | Prostate
---|---|---|---
Control | Navigated

Percent of Subjects

B C F A D G E B A D E C F C B
Some sites showed a navigation impact soon after abnormal screen.
Time to Diagnosis Curves

Others only showed a benefit for those with an initial delay.
Meta-analysis: Time to Diagnosis

aHR = 1.4 (95% CI 1.2 – 1.7)

Pooled effect for all sites found navigated subjects had more timely resolution
# PNRP Cancer Subjects

**N = 2,105**

## Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Navigated N=1032</th>
<th>Controls N=1073</th>
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<tr>
<td><strong>Age (mean)</strong></td>
<td>51.7</td>
<td>53.8</td>
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<td><strong>Race/ethnicity</strong></td>
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<tr>
<td>Black</td>
<td>37%</td>
<td>40%</td>
</tr>
<tr>
<td>White</td>
<td>28%</td>
<td>35%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>33%</td>
<td>20%</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
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<tr>
<td>Female</td>
<td>85%</td>
<td>86%</td>
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<tr>
<td><strong>Insurance Status</strong></td>
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<td></td>
</tr>
<tr>
<td>Uninsured</td>
<td>23%</td>
<td>11%</td>
</tr>
<tr>
<td>Public</td>
<td>43%</td>
<td>46%</td>
</tr>
<tr>
<td>Private</td>
<td>33%</td>
<td>43%</td>
</tr>
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</table>
Time to treatment

Pooled effect for all sites found navigated subjects *with initial delays* had more timely treatment

Treated within 90 days: $aHR = 0.79 \ (p=0.21)$

Treated after 90 days: $aHR = 1.63 \ (p=0.001)$
No significant difference in crude satisfaction scores

P > 0.05
PNRP Secondary Analyses

- Costs
- Quality of cancer care
- Barriers to care
- Navigation activities
Cost Consequence Analysis*

$290 per patient  vs.  usual care

- *Could* be Cost-effective if increase in timely care results in earlier stage at diagnosis

- No stage shift in PNRP but not powered

*Bensik M, Ramsey S, Mandelblatt J et al*
Quality Breast Cancer Care

Do navigated women meet National Comprehensive Cancer Network (NCCN) Category 1 Quality Measures for Breast Cancer more often than control patients?

Ko et al. ASCO 2012
NCCN Category 1 Quality Measures:

1) Hormonal Therapy within 1 year of diagnosis of HR+ tumors >1 cm

2) Post-lumpectomy radiation therapy

3) Chemotherapy within 120 days of diagnosis of hormone negative, >1 cm tumors for women <70 years of age
## Adjusted Odds Ratios for Quality Measures

*Adjusted for age, race, insurance, marital status and study design*

<table>
<thead>
<tr>
<th>Quality Measures</th>
<th>aOR</th>
<th>95% CI</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hormone Therapy</td>
<td>1.78</td>
<td>(1.22, 2.57)</td>
<td>0.002</td>
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<tr>
<td>Radiation Therapy post Lumpectomy</td>
<td>1.12</td>
<td>(0.70, 1.79)</td>
<td>0.643</td>
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<tr>
<td>Chemotherapy</td>
<td>0.48</td>
<td>(0.24, 0.95)</td>
<td>0.035</td>
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</table>
Boston PNRP  N=1,493

Number of barriers among navigated patients

- None
- One
- Two
- Three or more
Hooray - That ear is better...
Anything else...?
Social Service Barriers

- Barriers considered adverse social circumstances with potential legal remedies that reside in laws, regulations or policies

- Medical Legal Partnership framework I-HELP
  - I- Income Supports
  - H- Housing & Utilities
  - E- Employment & Education
  - L- Legal Status (Immigration)
  - P- Personal/Family Safety & Stability
<table>
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<tr>
<th>Social Service Barrier</th>
<th>Other Barrier</th>
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</thead>
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<tr>
<td>Housing</td>
<td>Transportation</td>
</tr>
<tr>
<td>Childcare Issues</td>
<td>Social/Practical Support</td>
</tr>
<tr>
<td>Adult Care</td>
<td>Language</td>
</tr>
<tr>
<td>Insurance (Uninsured, Underinsured)</td>
<td>Literacy</td>
</tr>
<tr>
<td>Financial Problems</td>
<td>Location of Health Care Facility</td>
</tr>
<tr>
<td>Employment Issues</td>
<td>Communication Concerns with Medical Personnel</td>
</tr>
<tr>
<td>Fear</td>
<td>Medical &amp; Mental Health Co-morbidity</td>
</tr>
<tr>
<td>Patient Disability</td>
<td></td>
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<tr>
<td>Out of Town/Country</td>
<td></td>
</tr>
<tr>
<td>Perceptions/Beliefs about Tests/Treatment</td>
<td></td>
</tr>
<tr>
<td>System Problems with Scheduling Care</td>
<td></td>
</tr>
<tr>
<td>Attitudes Towards Providers</td>
<td></td>
</tr>
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</table>
Barriers vary by site

<table>
<thead>
<tr>
<th>City</th>
<th>% subjects with Insurance Barrier</th>
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<tr>
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<td>2</td>
</tr>
<tr>
<td>Chicago</td>
<td>44</td>
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<tr>
<td>Denver</td>
<td>17</td>
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<td>Ohio</td>
<td>10</td>
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<tr>
<td>San Antonio</td>
<td>44</td>
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<tr>
<td>Tampa</td>
<td>60</td>
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<tr>
<td>Washington DC</td>
<td>11</td>
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</table>
Task and Social Network Analysis

- Direct field observation of navigator work*
- 8 PNRP sites and 10 Avon sites
- Found discrete patterns of navigators’ activities that vary by local context**
  - Location of navigation
  - Organization
  - Patient needs
  - Community resources

*Parker, Health Services Research 2010; **Clark et al HSR 2013
<table>
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<tr>
<th>Tasks/Network</th>
<th>Patient</th>
<th>Provider</th>
<th>Non-Clinical Staff</th>
<th>Support</th>
<th>EMR</th>
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<td>Navigate <strong>with</strong> specific pt</td>
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<tr>
<td>Facilitate <strong>for</strong> specific pt</td>
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<tr>
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</table>
Summary of PNRP Findings

- Navigation facilitates timely and quality care for certain populations:
  - Those with significant delays in care
  - Those with many or certain barriers
- No effect on satisfaction
- May be cost effective
- Certain navigation activities matter
- Substantial site differences suggest community specific needs differ
Future Challenges

1) The paradox
   - “If navigation is everything, it’s nothing”
     H. Freeman
   - Potential to widen the disparities gap

2) Sustainability
   - How do we integrate patient navigation into emerging health care delivery models?
Institute for Healthcare Improvement

New health care designs must achieve the “Triple Aim” (2007)

1. Improve the health of the population
2. Enhance the patient experience
3. Reduce, or at least control, cost of care.
Professional Organizations: Accreditation Standards

- National Accreditation Program of Breast Centers (NAPBC)
- National Comprehensive Cancer Network (NCCN)
- American College of Surgeons Commission on Cancer (CoC)
- National Committee for Quality Assurance (NCQA) Patient Centered Medical Home
2010 Affordable Care Act

- Landmark social welfare policy
- Majority of Americans who will gain health insurance coverage are in the bottom $\frac{1}{2}$ of the nation’s income distribution
- Potential to reduce racial health disparities
(Almost) no-one excluded
Increased role Primary Care
**Begins** the process to realign incentives within health care system
Reward providers for delivery of high value, patient-centered care
Pay for Volume → Pay for Quality
Already some benefits

Davies, K et al JGIM 2011
Patient Centered Outcomes Research Institute (PCORI)

- **Title VI: Transparency and Program Integrity**
- Separate from Agency for Healthcare Research and Quality (AHRQ)
- Comparative effectiveness research renamed
- Patient Navigation studies targeted
The Challenge of Re-defining success

- What is ‘patient-centered’ care?
- How do we measure it?
- How do you implement patient-centered care on a population level?
The Challenge of Scale

- We can manage a small population—more difficult as numbers grow
- We can only manage “our” patients—many not connected to care
- Data collection is resource intensive
- Education happens one patient at a time in the office
Where do we go from here to “repair the disconnect”? 
1. Advance the Science

- Compare best practices models
  - Target those most vulnerable
  - Address community-specific barriers
  - Standardize navigation competencies
- Monitor navigation activities
- Measure *patient-centered* outcomes
  - Patient identified barriers
  - Access to information and resources
2. Acknowledge
3. Innovations in Community Engagement

- Along the entire care continuum
- Beyond Community Advisory Boards
- Let the community redefine success
- Resource sharing:
  - Clinical Translational Science Institutes
  - MB-CCOPs
  - Prevention Research Centers
  - State Comprehensive Cancer Coalitions
  - American Cancer Society
Conclusions

- Patient navigation is one community-focused cancer care delivery model with promise to repair the disconnect
- Future innovations in cancer care delivery requires community specific solutions across all layers health care system
- Sustainability is dependent on scalability
- Connect the dots…..
Collaborators

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- Jack Clark PhD
- Tim Lash PhD
- Bonnie Sherman PhD
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- Azadeh Nasseh MD MSc
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- Michele David MD MPH
- Andrea Kronman MD MPH
- Victoria Parker DBA
- Sharon Bak
- Sarah Caron
- Sarah Primaeu
- MaryBeth Howard

Nationally
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- Northwestern
- Univ. Rochester
- Moffit, Tampa
- Ohio State
- Denver Health and Hosp.
- Univ. Texas, San Antonio
- George, Washington DC
- Portland Northwest
- NCI
- NOVA Research