Patient Navigation Research Program (PNRP)

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Patient Navigator Background

There is a critical disconnect between cancer discoveries and cancer care delivery to all American people.

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Cancer Care Barriers

Cancer Care Services

Cultural Barriers
- Fear of "research"
- Cancer is "contagious"
- Cancer is "punishment"
- Fear & stigma of cancer
- Do not ask questions
- Privacy
- Fear of Federal Government

Patient Barriers
- Frequent moves
- Education
- Communication
- Inflexible clinic hours
- Telephone
- Transportation
- Child- & Eldercare
- Comorbidities
- Insurance

Program & Administration Barriers
- Misconceptions about Navigator program
- Data collection
- Staffing
- Administrative approval
- Insurance

Navigator Barriers
- Comorbidities
- Trust
- Insurance
- Time involved working with outside agencies
- Non-Navigator clinic demands
- Cross-training
- Patients who lack family support
- Patient compliance

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General Framework of Patient Navigator Program

PATIENT NAVIGATION

OUTREACH

Initial Contact

Abnormal Finding

- Abnormal finding/diagnosis to resolution
- Eliminate critical delivery gap for populations experiencing disparities
- Test feasibility of Patient Navigation intervention concept
- Identify, test, and measure delivery improvement interventions that use Patient Navigators

Conclude Navigation

Resolution

REHABILITATION

Abnormal results/ Diagnosis ⟶ Diagnosis ⟶ Treatment ⟶ Survivorship

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NATIONAL CANCER INSTITUTE

Patient Navigator Possible Roles

Navigation
- Coping With Diagnosis & Treatment
- Education About Diagnosis & Treatment
- Adherence to Treatment Regimen
  - Tracking Hard-To-Reach patients
- Insurance
- Financial Assistance
- Communication With Clinicians
- Transportation Issue
- Temporary Housing
- Family Support Resources
- Navigator Database

Clinical Trials
- Encourage Enrollment
- Consent Translations

Outreach
- National Programs
- Health Fairs
- Local Workshops

Cancer Screening
- Monitor National Guidelines
- Screening Program Prostate, Breast, Cervical, Colorectal
- Screening Database

Collaborations & Partnerships
- Oncology Providers & Local Tumor Board
- Survivorship Groups
- Local Agencies
- Transit
  - Bus
  - Taxi

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NCI PNRP Sites

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Cancer Sites To Be Examined

	Breast	Cervical	Colorectal	Prostate
Chicago	✓	✓	✓	✓
UT—San Antonio	✓	✓		
University of Rochester	✓		✓	
Boston University	✓	✓		
Northwest Indian Health	✓	✓	✓	✓
Ohio State (ACS funded)	✓	✓	✓	
GWU—Washington, DC	✓			
Denver HHA	✓		✓	✓
Moffitt—Tampa	✓		✓	

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Patient Navigation Research Program

Goal:

To develop patient navigation interventions to reduce, and ultimately eliminate, disparities in cancer clinical outcomes related to lack of timely access to culturally sensitive, quality, standard cancer care (diagnosis and treatment) among populations who often experience the greatest burden of cancer.

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Capturing Expected Outcomes Evaluation Questions

Outcome

- Time:
  - Abnormal finding to diagnosis
  - Diagnosis to initiation of treatment
  - Initiation of treatment to end of primary treatment
- Patient satisfaction with navigators, navigation, and cancer care delivery system
- Improvement in Quality of Life
- Cost-effectiveness

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Capturing Expected Outcomes Evaluation Questions

Process

- Navigator interventions
- Navigator training, competency, case load
- Matching patient / navigator
- Professional vs. lay navigator
- Community (social) networks

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Common Data Elements

Patients

- Demographics
- Socioeconomic status
- Family history
- Co-morbidity

Instruments

- Satisfaction with care
- Satisfaction with PN
- REALM
- SMAS
- IES
- CASE-General
- CASE-Cancer

Resources & Costs

Cancers

- Breast
- Cervical
- Colorectal
- Prostate

Eligibility
Diagnostic work-up
Definitive diagnosis
Stage of disease
Clinical trials
Treatment

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Common Data Elements

Patient Navigator

- Demographics
- Socioeconomic status
- Activities / actions

PN Tracking Log

- Patient barriers
- PN activities

PN Performance Checklist

- Client interaction
- Care management
- PN intervention
- Documentation

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Use Of PNRP Evaluation Findings

- Lessons learned and best practices
- Support patient access to cancer care system
- Assess impact of patient navigation on timely receipt of cancer care
- Encourage collaborations and partnership
- Support long-term research to eliminate cancer health disparities
- Determine if patient navigation can be delivered cost-effectively to warrant insurance reimbursement

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Chicago Cancer Navigation Project

Elizabeth Calhoun, University of Illinois at Chicago

NCI Grant #: U01 CA116875-01

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Chicago Goal

- Develop a patient navigator intervention for lower-income patients in Chicago, Illinois who need follow-up care for positive cancer screening tests of the
  - prostate and colorectum (VA)
  - breast and cervix (ACCESS)

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Prostate and Colorectal Cancers: Veterans Administration

- Site characteristics:
  - Equal access system in major urban center
- Population characteristics:
  - Over half of the patients are racial/ethnic minorities
  - Almost all have lower socio-economic backgrounds
  - Over half are older than 65 years
  - One-fifth have limited health literacy skills
- Study Site:
  - In 2004 there were 7,600 inpatient visits and 531,000 outpatient visits, serving 62,000 Veterans.

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Breast and Cervical Cancers: Access Community Health Network

- Site characteristics:
  - Largest community health center (authorized under section 330 of the PHS Act) in the country, with 48 sites-700,000 visits
- Population characteristics:
  - 45% African American, 55% Latino
  - 60% Medicaid, 25% Uninsured, 10% Medicare
- Study sites:
  - ~43,000 visits annually
    - ~40% African American
    - Mean age = 38

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The Patient Navigator Team

- A multi-tier, care management **team** that will include:
  - a clinical social worker (lead navigator)
  - a nurse clinician, and
  - a lay health navigator

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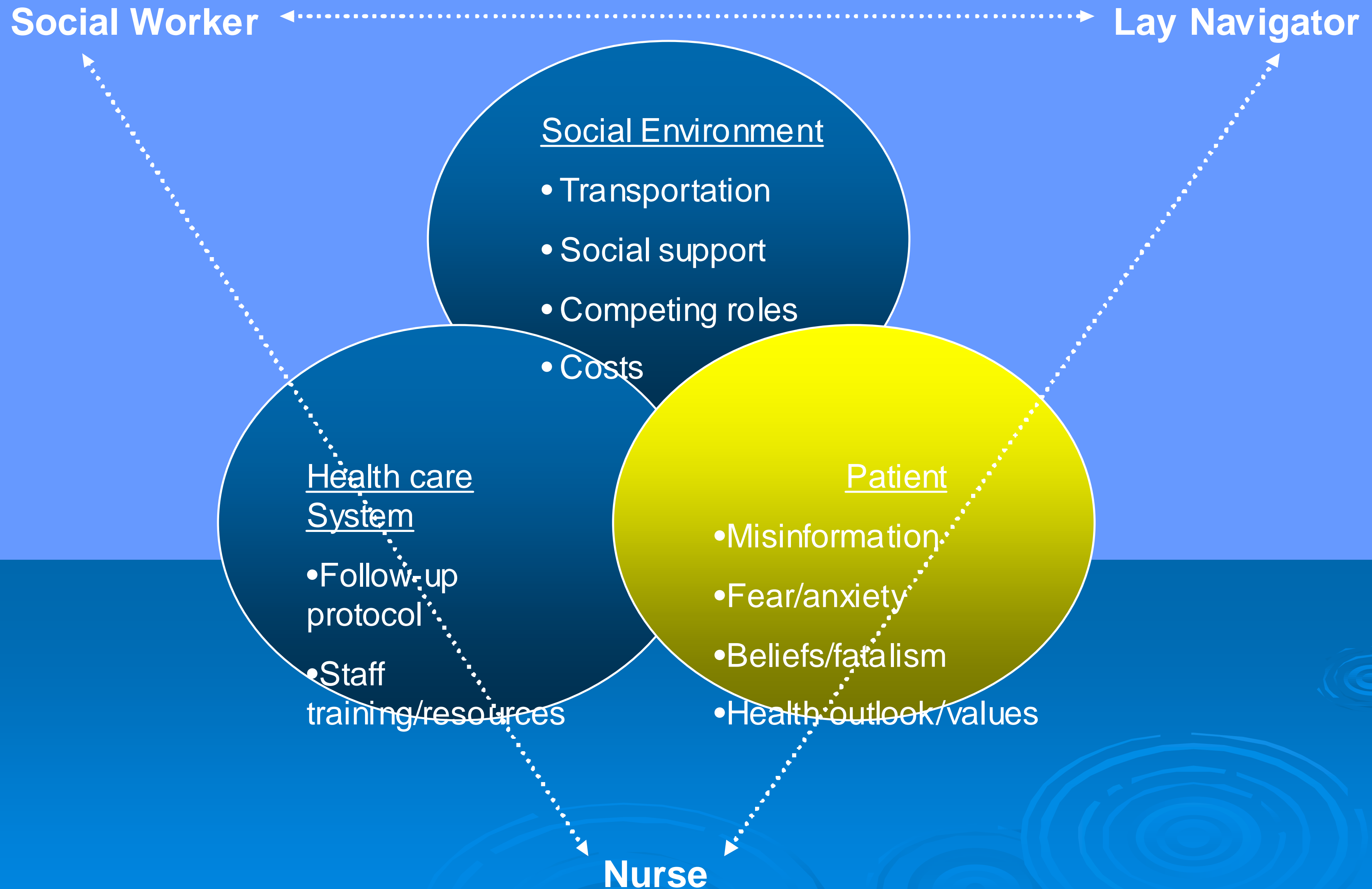

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Clinical Social Worker

- **Lead Navigator**
- **Roles and responsibilities**:
  - Conduct a rapid assessment of psychosocial needs for all patients identified as having an abnormal screen
  - Leads/supervises treatment planning
  - Part of the larger American Cancer Society Navigation program, which has a statewide network of resources that will be utilized by navigation program

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Nurse Clinician

- Roles and responsibilities:
  - Maintain primary responsibility for team clinical support
  - Responsibilities begin immediately after a patient has a positive screening test by initiating communication with both the patient and clinical social worker
  - Contact patients with positive screens
  - Interpret the results of abnormal screens
  - Schedule/Supervise appropriate follow-up diagnostic tests

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Lay Health Navigator

- Roles and responsibilities:
  - Identify barriers to accessing care (e.g., no transportation, limited literacy, no child care, difficulty obtaining time off from work)
  - Support the patient in problem solving to overcome them
  - Remind the patient about appointments
  - Accompany the patient to the visit/make arrangements for transportation
  - Make home visits for patients at risk for being lost to follow-up

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Without Navigation

- **% of patients who did not follow up after receiving abnormal screen:**

  - Prostate cancer: **30%**
  - Colorectal cancer: **50%**

  - Breast cancer: **52%**
  - Cervical cancer: **56%**

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Patient Demographics

Age		33.20 (sd14.53)
Education	Less than high school diploma	27.8%
	High school diploma and more	72.3%
Household income	Less than $10,000	56.2%
	Between $10,000 and $29,999	38.8%
	$30,000 and more	5.0%
Employment status	No current employment	48.4%
	Part-time employment	23.4%
	Full-time employment	28.2%
Health insurance	No health insurance	52.6%
	Medicaid only	31.6%
	Medicare only	0.8%
	Other	15.1%

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Lessons Learned

- Social Worker
  - Able to handle complex psychosocial issues
  - Enables lay/peer to do more tasks with support
  - Leads treatment planning meetings
  - Internal team building
  - Knowledgeable of resources
    - Patient X – starting chemotherapy – no utilities

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Lessons Learned

- Nurse Clinician
  - Crucial clinical support for team
    - Eligibility
    - Education
    - Resources
  - Able to candidly discuss medical information with difficult patients when able to find on phone or in-person
  - Do not need full-time support- PRN

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Lessons Learned

- Lay/Peer
  - Highly dedicated and motivated
  - Knows community
  - Need some level of professional support to function independently
  - Need help to integrate into the medical team/professional staff
  - Empathy with personal experience

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Questions

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