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CENTER FOR THE ADVANCEMENT OF
CANCER SURVIVORSHIP, NAVIGATION AND POLICY

**National Patient Navigation Collaborative
Inaugural Meeting Summary
December 9, 2011**

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**National Patient Navigation Collaborative Inaugural Meeting Summary
Table of Contents**

Executive Summary.....1

Meeting Summary.....2

Appendix A: Background Document.....13

Appendix B: Meeting Agenda.....20

Appendix C: Attendee List.....22

Appendix D: List of Acronyms.....24

National Patient Navigation Collaborative Inaugural Meeting Executive Summary

On December 9, 2011, the George Washington Cancer Institute's Center for the Advancement of Cancer Survivorship, Navigation and Policy hosted the first meeting of the National Patient Navigation Collaborative in collaboration with the American Cancer Society and the University of Illinois at Chicago--a first-of-its-kind effort to leverage the expertise and experience of diverse stakeholders to develop and implement a strategic plan to support patient navigation as an integral part of the health care system. Thirty-nine participants represented twenty organizations including professional societies, academic institutions, training programs and advocacy organizations. The meeting focused on identifying a policy framework for advancing patient navigation, learning from successful community health worker models and moving towards a strategic plan. Participants:

- Agreed on the need to come together in a coordinated effort to develop and implement a strategic plan to support patient navigation as an integral part of the health care system.
- Recognized time pressures related to implementation of the Affordable Care Act and to increasing use of the term that threatens to dilute its meaning
- Identified the need to clearly define the terms patient navigation and patient navigator and distinguish them from other interventions and professions.
- Adopted Dr. Freeman's 9 Principles of Patient Navigation as the framework for the collaborative's work.
- Reiterated the need to include more diverse stakeholders.
- Recommended clarity around the consortium management and structure.
- Agreed on the following next steps:
 - Create a formal network
 - Propose a set of core competencies
 - Develop a white paper consensus report
 - Explore policy options
 - Develop a repository of information
 - Identify infrastructure needs
- Proposed a workgroup structure to continue engagement:
 - Executive Committee
 - Governance & Membership Committee
 - Repository Committee
 - Core Competencies & Trainings Committee
 - Scientific Advisory Group
 - Sustainability Committee
 - Policy Committee
 - Dissemination and Communications Committee

National Patient Navigation Collaborative Inaugural Meeting

Patient navigation is gaining momentum as it is increasingly recognized as an intervention for improving access to care for cancer patients across the survivorship continuum. In 2005, President Bush signed into law the Patient Navigator Outreach and Chronic Disease Prevention Act, and the National Cancer Institute's (NCI) Center to Reduce Cancer Health Disparities funded eight sites and the American Cancer Society (ACS) funded one site for the Patient Navigation Research Project (PNRP). In 2006, the Centers for Medicare and Medicaid Services (CMS) funded six demonstration projects to study patient navigation,¹ and the Health Resources and Services Administration has funded 16 patient navigation demonstration projects since 2008.^{2,3} The 2010 Patient Protection and Affordable Care Act (ACA) also calls attention to patient navigation and authorizes navigation demonstration projects. Patient navigation is clearly a federal priority, and growing evidence from PNRP and other studies suggests that patient navigation is an effective intervention.^{4,5,6,7}

Patient navigation has also been identified as a critical component of cancer care by several influential national organizations. In 2008, a U.S. Surgeons General collective issued a *National Call to Action on Cancer Prevention and Survivorship* and listed patient navigation as one of four priority areas required to make progress in the War on Cancer;⁸ the Association of Community Cancer Centers (ACCC), has made patient navigation a priority in its ACCC Cancer Program Guidelines;⁹ and the Commission on Cancer (CoC) announced several new patient-centered requirements for accreditation to be phased in by 2015, one of which requires a patient navigation process. CoC institutions provide care for approximately 70% of the 1.5 million newly diagnosed patients each year.¹⁰

In 2010 the American Cancer Society (ACS) hosted the National Patient Navigation Leadership Summit and brought together leaders in the field to establish common measures for navigation across the cancer continuum. The 115 participants represented over 65 organizations and included clinicians, researchers, public health experts, funders and patient navigators. Results published in fall 2011 laid out a framework for the principles of navigation as well as defined measures for navigation across the cancer continuum, including prevention and early detection, diagnosis and treatment, post-treatment survivorship, and palliative care, as well as partnership approaches, patient-centered outcomes and cost measures. Establishing common measures will contribute to the evidence base needed to change policy to support the sustainability of patient navigation as a profession.

With this momentum, now is a critical time for advancing the role of patient navigation at the national level and overcoming some of the key challenges for the field. Recognizing the need for a coordinated multi-year effort, the George Washington Cancer Institute (GWCI), the American Cancer Society (ACS) and University of Illinois at Chicago (UIC) collaborated to launch the National Patient Navigation Collaborative (NPNC). The goal of this initiative is to work with key stakeholders to develop and implement a strategic plan to support patient navigation as an integral part of the health care system. The inaugural in-person meeting was held in Washington, DC on December 9, 2011. This report serves as a summary of the meeting. The background document sent to participants in advance, the meeting agenda and a list of meeting attendees can be found in the Appendices.

Introduction

One of the objectives of the NPNC is to speak as one voice to further the goals of patient navigation with a focus on the patient. Some areas of perceived general agreement from a preliminary group discussion about the NPNC are:

- There is a sense of timeliness and urgency. It is critical that the NPNC come together quickly and move quickly. Without this collaborative voice to define and/or promote navigation, others who have a varying understanding of the role of patient navigation will do that for us.
- Patient navigation is important as an intervention for many diseases (not just cancer). Many providers, from lay persons to social workers to nurses to physicians, serve navigation functions. Patient navigation is a set of principles and functions to overcome barriers and obtain access to care.
- There is a critical need for a unified voice for the field. A consortium model is proposed to speak as one voice to advance and sustain patient navigation.

Session I: Framework for Developing Patient Navigation as Part of the Health care Workforce

The purpose of this session was to understand a framework to advance patient navigation policy. With the discouraging atmosphere in Congress after the failure of the Super Committee, now is an ideal time to show Congress and the world that we can deliver on patient-centered care. People are living longer and dealing with more illness, and caregivers are strained, as well. Predicted widespread workforce shortages threaten our capacity to provide appropriate care. The workforce shortage combined with the growing population of cancer survivors in the context of health reform implementation focus the group's efforts.

Value = improved quality / reduced cost. The collaborative needs to be careful of how they use buzzwords in the wake of the Affordable Care Act (ACA)--such as shared decision-making, value-based purchasing, medical home, coordinated care, comparative effectiveness, reducing cost and new models of workforce development. It is important to be sure we know what we are talking about and convey real meaning with our communication. The group needs to "jump on the train" promising patient-centered care by communicating that patient navigation has a central role in addressing barriers to seeking and completing health treatment and improving communication with care teams.

Policy is an important focus for this effort. Ideally, the goal is to have evidence-based decision-making, but policymakers often do decision-based policy-making, meaning that many policies are not made based on evidence. Below is an overview of the five step planning process for federal and state policy development:

1. Identify the system problem(s) you want to address

- Fragmentation and complexity
- How can we deliver on this concept of patient-centered care

The group needs to align messages to show how patient navigation addresses health system fragmentation and complexities. This starts with developing consensus around defining who

patient navigators are, what they do and how they help patients. Patient navigation should be positioned as an opportunity to address the workforce problem, remove barriers and improve outcomes and provide a patient-centered care experience. Without a unified message from the navigation community, policymakers have an excuse to do nothing.

2. Articulate the goals you want to achieve (as a consortium)

- Reduce barriers to care / reduce fragmentation through patient navigation

An example goal is: By 2020, patient navigation will be viewed as an integral part of health care teams (and navigators will serve an essential aspect of delivering high-quality care). All patients and families will understand and have access to patient navigation services to support them through the health care system. All health professionals will understand and tap the expertise of navigators to provide navigation support for patients and families. All hospitals and other care settings will be set up to use patient navigators and navigation to improve access to coordinated and patient-centered care.

3. Consider available policy approaches that can be solutions

- What are the system solutions at the policy level (workforce, training, payment)?

Options may include improving public and professional understanding of patient navigation to drive demand; encouraging expansion of funding opportunities; supporting workforce and training programs; or establishing reimbursement mechanisms for patient navigation services.

4. Examine the existing policy/legislative landscape

- Conduct a literature review to determine gaps and solutions

We need to better understand the implications of the ACA on patient navigation, including how navigation can converge with quality measures, education and training opportunities and career awards under the ACA. . We should leverage past legislation such as the Patient Navigation Outreach and Chronic Disease Prevention Act of 2005 and new efforts like the ACS Cancer Action Network's quality of life legislative platform: "Patient-Centered Quality Care for Life Act."

5. Develop new proposals forging further ground

- Based on lit review & gap analysis

It is not enough to simply educate policymakers. There needs to be a clear ask with a clear message crafted. Essential elements of effective advocacy include:

- *Message:* We must be able to say, "We want you to do x (support this bill, commission a study, etc)"
- *Evidence:* Research must be provided to support the message.
- *Stories:* Patients represent a critical grassroots force

Finally, the Campaign Planning Direct Action Organizing Formula is:

- Develop a clear ask

- Articulate goals – short- and long-term wins
- Identify stakeholder allies for coalition support
- Strategic pursuit of congressional champions/supporters
- Grassroots education – develop tactics for engagement
- Media to showcase your cause
- Apply pressure

The new Commission on Cancer navigation standard, interest by the Joint Commission on Accreditation of Health care Organizations in accrediting patient navigators and the American Medical Association’s recent position statement on patient navigation should inform policy strategies. To focus our efforts, the group may wish to start by addressing the “low-hanging fruit” by focusing on developing core competencies, creating a standardized curriculum and implementing structured trainings.

Session II: Learning from the Community Health Worker Models

The purpose of this session was to discuss the main challenges and strategies to be used to advance the community health worker field that can be applied to patient navigation. To focus the discussion, two presenters were invited to talk about success within the community health worker (CHW) field in training and certifying CHWs.

Minnesota was successful in attaining reimbursement for CHWs. The successful process used was:

1. Define CHW
2. Create a standard curriculum
3. Attain approval from the Department of Labor for an Standard Occupational Classification for CHWs
4. Develop scope of practice for CHWs
 - a. Role 1: Bridge the gap between communities and the health and social service systems
 - b. Role 2: Navigating the health and human services system
 - c. Role 3: Advocate for individual and community needs
 - d. Role 4: Provide direct services
 - e. Role 5: Build individual and community capacity

Partnerships were a critical factor for success, and partners included educational institutions, state agencies, state associations, non-profit organizations, payers, industry, CHWs, foundations and national organizations. Curriculum development took two years and started with a 9-credit hour non-disease-specific program focused on skills to perform the job. After receiving feedback from participants, they added a 3-credit hour health promotion section and a 2-credit hour internship program, which helped get the word out about CHWs but is very time consuming to coordinate. It is critical to move policy along with the curriculum because there must be positions available for graduates after they have been trained. The curriculum is outlined below:

- Role of the CHW – Core Competencies (9 credit hours)
 - Role, Advocacy and Outreach - 2
 - Organization and Resources - 1
 - Teaching and Capacity Building - 2

- Legal and Ethical Responsibilities - 1
- Coordination and Documentation - 1
- Communication and Cultural Competency - 2
- Role of the CHW – Health Promotion Competencies (3 credit hours)
 - Healthy Lifestyles
 - Heart and Stroke
 - Maternal Child and Teens
 - Diabetes
 - Cancer
 - Oral Health
 - Mental Health
- Role of CHW – Practice Competencies – Internship (2 credit hours)

A 2008 Minnesota statute was critical for CHWs. It provided CHWs with their own Medicaid provider number and established that supervision must be provided by a state Medicaid-enrolled physician, advanced practice nurse, mental health professional, dentist or certified public health nurse operating under the direct authority of an enrolled unit of government. Several components of the ACA are relevant to promotion of CHWs. Massachusetts, New Mexico, Texas, New York, Oregon, Rhode Island and Arizona are other states with CHW programs. The main challenges and strategies related to Minnesota’s efforts include:

- Territory
- Training – certification is essential.
- Ten Cents – must determine funding mechanisms
- Teachers
- Terminology – the group needs to all have the same elevator speech
- Turf – must define who patient navigators serve and whether patient navigators and CHWs are the same. We must be clear about how patient navigators complement other professions.

The Gateway to Care (GTC) Access Collaborative in Texas has also been successful in promoting the role of CHWs. Their definition of CHW is a person who, with or without compensation, provides a liaison between health care providers and patients through activities that may include activities such as:

- Assisting in case conferences,
- Providing patient education,
- Making referrals to health and social services,
- Conducting needs assessments,
- Distributing surveys to identify barriers to health care delivery,
- Making home visits, and
- Providing bilingual language services.

The State of Texas certifies individuals who complete a 160-hour (20 hours per competency) training course that covers 8 core competencies:

- Communication Skills

- Listening
- Use language confidently and appropriately
- Ability to read and write well enough to document
- Activities
- Interpersonal Skills
 - Counseling
 - Relationship-building
 - Ability to work as a team member
 - Ability to work appropriately with diverse groups of people
- Service Coordination Skills
 - Ability to identify and access resources
 - Ability to network and build coalitions
 - Ability to provide follow-up
- Capacity-Building Skills
 - “Empowerment”- Ability to identify problems and resources to help clients solve problems themselves
 - Leadership
 - Ability to strategize
 - Ability to motivate
- Advocacy Skills
 - Ability to speak up for individuals or communities and withstand intimidation
 - Ability to use language appropriately
 - Ability to overcome barriers
- Teaching Skills
 - Ability to share information one-on-one
 - Ability to master information, plan and lead classes, and collect and use information from community people
- Organizational Skills
 - Ability to set goals and plan
 - Ability to juggle priorities and manage time
- Knowledge Base on Specific Health Issues
 - Broad knowledge about the community
 - Knowledge about specific health issues
 - Knowledge of health and social service systems
 - Ability to find information

Each certification cycle is two years, and CHWs are required to have at least 20 hours of continuing education during that time. Not only are CHWs certified, but instructors and institutions must be certified in order to provide the training. The GTC Community Health Worker Training Institute has graduated 379 people since 2005, and graduates are now working in hospitals’ ERs and specialty departments, clinics, community- and faith-based organizations, health plans, churches and communities.

Session III: Navigator Training Models

History and Overview

The 1989 Report to the Nation on Cancer and the Poor found that:

- Poor people meet significant barriers when they attempt to seek diagnosis and treatment of cancer.
- Poor people often do not even seek care if they cannot pay for it.
- Poor people experience more pain, suffering, and death because of late stage disease.
- Fatalism about cancer is prevalent among the poor and prevents them from seeking care.
- Poor people and their families must make extraordinary and personal sacrifices to obtain and pay for care.
- Current cancer education programs are culturally insensitive and irrelevant to many poor people.

Dr. Harold P. Freeman developed the concept of patient navigation in response to this report and the recognition that people in Harlem faced significant barriers to access care and needed assistance before they were even diagnosed with cancer. Over time the concept of patient navigation has been expanded across the continuum.

Dr. Freeman's 9 Principles of Patient Navigation are:

1. Navigation is a patient-centric health care service delivery model.
2. Patient navigation serves to virtually integrate a fragmented health care system for the individual patient.
3. The core function of patient navigation is the elimination of barriers to timely care across all segments of the health care continuum.
4. Patient navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of other providers.
5. Delivery of patient navigation services should be cost-effective and commensurate with the training and skills necessary to navigate an individual through a particular phase of the care continuum.
6. The determination of who should navigate should be determined by the level of skills required at a given phase of navigation.
7. In a given system of care there is the need to define the point at which navigation ends.
8. There is a need to navigate patient across disconnected systems of care, such as primary care sites and tertiary care sites.
9. Patient Navigation systems require coordination.

The 2005 Patient Navigation Outreach and Chronic Disease Prevention Act of elevated patient navigation, and there was a large amount of national activity from 2004 to 2008 related to patient navigation. Now is the time to concentrate on moving to the next level in the field of patient navigation beyond these principles. A coalition is needed to move to the next political level.

Colorado Workforce Development Model

Colorado has developed a patient navigator workforce development model. In this model, CHWs represent the link to the health care system and focus on outreach to their neighbors in their own community. There are two levels of patient navigators; level 1 navigators work in both the community and health care system, while level 2 navigators are based within the system. The training programs are considered pathways out of poverty for many of the participants.

Colorado's CHW education program is a standardized, performance-based certificate program at the Community College of Denver that has existed since 2000. It is comprised of 17 credit hours that can be applied to a degree. The program costs \$2,400 per student and is paid for by employers, grants and scholarships so there is no cost to students. The curriculum includes:

- Workplace/Academic Core: 9 credit hours
 - Communication in Health care
 - Introduction to PC Applications
 - English Composition I
- Vocational Core: 6 credit hours
 - Community Health Issues
 - Community Health Resources
- Field Experience: 2 credit hours

Housed at the University of Colorado School of Public Health, the patient navigator training program is funded by tobacco settlement funds and is a collaborative of multidisciplinary content and training experts. Navigators include lay, paraprofessionals or allied health professionals (CNA, CAC), health care professionals (RNs, LCSWs, “Boomers”) and unlicensed professionals from other countries. A challenge in developing the training program was meeting the training needs of a diverse workforce while assuring knowledge and skill attainment met core patient navigator competencies and enhanced practice. To address this challenge, they developed multi-level and multi-modal trainings.

GWCI Patient Navigation Trainings

GWCI follows a longitudinal model of patient navigation across the cancer continuum. Community outreach specialists promote wellness in the community and promote access to screening, and patient navigators are seen as a bridge to address structural and social barriers. Additionally, GWCI administers the DC Cancer Consortium-funded Citywide Patient Navigation Network that promotes connectivity among patient navigators in DC. GWCI offers monthly professional development opportunities for the patient navigators and provides core coordination and resource mining functions for the network.

GWCI also offers two tiers of patient navigation training. The skills-based training entitled “Patient Navigation Training: From Outreach to Survivorship” is provided through GWCI’s Center for the Advancement of Survivorship, Navigation and Policy (caSNP), initially funded through Pfizer Foundation and Pfizer Inc.’s Global Health Partnership program. The target audience is patient navigators, social workers, nurse navigators and other medical and lay personnel interested in patient navigation. The format is a three-day in-person training in Washington, DC, that promotes networking among speakers and participants to create supportive and educational relationships. It employs a combination of lecture, role play and interactivity through case studies.

The second tier, executive-level training entitled “Executive Training on Navigation and Survivorship Program Development” is targeted to clinicians, administrators and staff at institutions that provide care to cancer patients and survivors as well as those who wish to establish navigation and/or survivorship programs at their institution. It employs a combination

of distance-learning and traditional classroom instruction through a pre-course online webinar and a two-day in-person training in Washington, DC. The content and curriculum are developed and delivered by collaborative team of survivorship and navigation experts. The caSNP listserv is an important communications vehicle for trainees as it helps to communicate upcoming events and programs, reports, resources and timely information related to patient navigation and survivorship and serves as a networking tool, connecting hundreds of clinicians, researchers, and health professionals from government, academia, hospitals and cancer centers across the nation.

Sessions IV and V: Moving Towards a Strategic Plan and Measuring Progress

These sessions focused on continuing the discussion about the strategic plan and was an open forum for participants to ask questions. The group identified other stakeholders who should be considered:

- Federally Qualified Health Centers (FQHC)
- Other community members
- Payors
- More diverse representation
- Reed Tuckson, the medical director of one of largest health insurance plans and former Commissioner of Public Health for the District of Columbia
- Eduardo Sanchez at Blue Cross Blue Shield and former Texas Commissioner on Health, who knows the issues for immigration
- Patient Advocate Foundation
- Health economists
- Accountable Care Organizations
- State primary care associations
- Non-cancer groups
- Patient advocate representatives
- Bioethicists (it was mentioned that Dr. Whitley is a bioethicist)

Next steps are to identify and agree on general principles and then continue to refine specific goals for the Collaborative. Suggested goals include:

- Standardized training
- Developing a set of core competencies
- Develop a national training
- Create repository of resources, trainings, webinars, etc.
- Capture common metrics

The group discussed developing core competencies for patient navigators. The group should start with the common core competencies of existing patient navigation trainings, which had been compiled and sent to participants in advance. The competencies do not need to be discrete as many health professions share similar competencies, and the group should work with other groups, such as the Oncology Nursing Society (ONS) and National Association of Social Workers (NASW), that already have developed competencies and garner agreement among these professional groups regarding patient navigation competencies.

The group discussed policy approaches and interim steps that can be taken, focusing on advocating for an IOM report on patient navigation. The IOM is an independent body so their scholarly work has a high level of authority for policymakers. For example, health disparities was not on the radar of policymakers until the IOM's *Unequal Burden of Cancer* report, which was spurred by the Intercultural Cancer Council. While there may be limited evidence to support patient navigation as it is an emerging profession, the IOM would search through all available evidence, including relevant evidence outside of cancer patient navigation. There was similarly limited data on survivorship when the IOM crafted the 2006 *From Cancer Patient to Cancer Survivor: Lost in Transition* Report, but the IOM's recommendations effectively catalyzed a national conversation around cancer survivorship.

To move the field of navigation forward, it is likely that we will need to expand the coalition across diseases. Patients do not have cancer or pain or heart disease alone; they have co-morbidities. We need to determine what role patient navigation has in getting patients through the health care system and addressing various health needs. The NPNC can be a body that focuses organizational efforts around patient navigation to perform a meaningful intervention for patients.

A report may be needed on workforce issues. C-Change released a workforce study, and with the shortage among doctors, nurses and social workers, patient navigators can help broaden the workforce. The IOM also released its Allied Health Workforce and Services workshop summary on December 8, 2011, and C-Change has established competencies for cancer health care professionals. A different way to frame the issue may be around addressing health disparities rather than focusing strictly on the profession of patient navigation.

Policy opportunities and strategies include:

- Improve public and professional understanding of navigation and drive demand.
 - Examples: request workforce study, IOM report and/or training/awareness grants
- Authorize funding to support research that will build evidence base and guide practice.
 - Examples: request NIH grants that call for navigation research, include those who understand patient navigation in study sections; and/or develop quality measures for patient care that include navigation
- Support the workforce and expand training.
 - Examples: request career development awards, loan forgiveness, grants for leadership centers and faculty training
- Position patient navigation as a policy solution to address disparities in access and care
- Provide reimbursement for navigation services and/or provide payment incentives for care that includes navigation services (build a sustainable model)
- Consider Center for Medicare and Medicaid Innovation (CMMI) funding opportunities

Session VI: Next Steps: Implementing the Strategic Plan

This session focused on identifying action steps to develop a consortium and discussed potential workgroups. The group adopted Dr. Freeman's 9 Principles of Patient Navigation as a framework to identify core competencies and policy options. The group then generally agreed on the following next steps:

- Develop a formal network of participants and identify others that need to be included in the collaborative
- Propose a set of core competencies that align with Dr. Freeman's Principles of Patient Navigation
- Develop a consensus report (white paper) on patient navigation
- Explore policy options, such as commissioning an IOM report, advocating for a workforce study, developing a strategy for approaching the HHS Secretary, talking to the CMMI, approaching policy makers who are already engaged on the issue, hosting open hearings on navigation, etc.
- Develop a repository of information for navigators and professionals who have or are interested in developing navigation programs
- Identify infrastructure to continue the effort, such as
 - Coalition dues (sliding scale)
 - Organization as voluntary lead
 - Workgroups to carry out objectives

Potential NPNC workgroups were discussed, and the group suggested:

- Executive Committee
- Governance & Membership Committee to lay out the collaborative infrastructure
- Repository Committee to identify best practices and catalog them on a web site
- Core Competencies & Trainings Committee
- Scientific Advisory Group to ensure data and evidence are infused into all discussions
- Sustainability Committee
- Policy Committee
- Dissemination and Communications Committee

Conclusions

The first meeting of the NPNC brought together a group of stakeholders to develop a strategic plan for supporting patient navigation as an integral part of the health care system. Based on a policy framework, the group outlined potential next steps to formalize the collaborative. General consensus was achieved on the following next steps:

- Create formal network
- Propose set of core competencies
- Develop a white paper consensus report
- Explore policy options
- Develop a repository of information
- Identify infrastructure needs

Appendix A: Background Document

The Institute of Medicine's report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health care*, calls attention to disparities in quality care and delivery for racial and ethnic minorities and the uninsured that continue to plague the health care system in the United States (U.S.). Patient navigation is a culturally competent intervention that has been used to address health disparities and access to care and quality care issues in the U.S. Patient navigation was pioneered in the 1990's by Dr. Harold Freeman as a way to reduce cancer disparities among the poor in Harlem, New York. Though originally designed to assist women through screening, diagnosis and treatment of cancer, the positive results of the intervention have led to expansion across the entire cancer continuum with widespread replication of the program across the country and in various diseases such as diabetes, heart disease and HIV/AIDS. As patient navigation programs have flourished around the nation, patient navigators vary in education, skill set, role and responsibility. The issue of sustainability is a significant financial challenge to patient navigation since it is not a reimbursable service in the health care system. Currently, while several training programs exist, there is no national training or credentialing standard to solidify patient navigation as a professional field in the health care system. Success from community health worker models to professionally integrate in the health system in Alaska, Indiana, Texas, Massachusetts and Minnesota may offer insight that applies to patient navigation to overcome these challenges. Local, regional, state and national stakeholders must collectively address the issues of defining patient navigation and scope of work, identifying core competencies for training programs, creating and authorizing an accreditation body and advocating at the local, state, and national level for health policy change that leads to the financial sustainability of patient navigation services. To address some of these challenges in making patient navigation an integral part of the health care system, the George Washington University Cancer Institute (GWCI), the American Cancer Society (ACS), and the University of Illinois at Chicago (UIC) have partnered to create the National Patient Navigation Collaborative. The initiative involves bringing together key stakeholders in patient navigation to address these issues and formulate a plan to integrate patient navigation as a profession in the health care system. This document serves as background information for the Collaborative's first in-person meeting in Washington, D.C. on December 8-9, 2011.

Defining Patient Navigation

One of the key challenges in patient navigation is the need to clearly define terms and roles to distinguish it from existing health care professions. Patient navigation can be described as an intervention to reduce health disparities in cancer care, specifically aimed at vulnerable or medically underserved populations and functions as a system.¹¹ Patient navigation can include not only patients but also providers, families and caregivers, and extend throughout the cancer continuum from prevention and screening through post-treatment and survivorship.¹² The National Cancer Institute (NCI) describes patient navigation as the support and guidance provided to persons with abnormal screenings or new cancer diagnoses, including overcoming challenges and barriers to accessing the health care system in a culturally competent manner.¹³ GWCI has expanded this definition to include a "longitudinal" model from outreach to survivorship.¹⁴ The Oncology Nursing Society, Association of Oncology Social Work and the National Association of Social Workers built on C-Change's cancer care definition to emphasize individualized assistance to patients, families and caregivers that also incorporates psychosocial

care from pre-diagnosis and throughout the entire cancer continuum.¹⁵ To move patient navigation forward, the cancer community will need to develop and agree upon a streamlined definition that can be promoted by all stakeholders.

Originally used to describe trained community health workers who navigate patients throughout the health care system, today navigators are typically health professionals or trained outreach workers with specific roles throughout the cancer continuum who work as a multidisciplinary team.¹² Different types of navigators can include non-clinical lay or peer navigators, usually trained workers from the community, and clinical navigators such as a social worker or nurse navigator with a specialized focus. The levels can be further divided into subspecialties such as an oncology nurse navigator or advanced practice nurse (APN) navigator. Despite the varying role, the main responsibility of patient navigators is to guide the patient through the health care system and eliminate barriers to care.¹¹ Barriers can include the geographic location of the clinic, center or hospital, financial services and insurance coverage, transportation and child care issues, lost wages, language and cultural issues, health belief systems and mistrust between patient and provider.^{12,13} Patient navigators connect patients with resources and support services, coordinate and schedule appointments, provide a link between the patient and physician, alleviate the administrative burden of medical paperwork and reduce fear and anxiety.¹² The Association of Community Cancer Centers issued a set of guidelines using C-Change's definition of patient navigation that outlined the characteristics of patient navigation services of trained volunteer and non-clinical navigators. As patient navigation programs have been used to reduce race and ethnic disparities within the health care system, each program is tailored to a specific population, though all navigation programs are centered on the goal of removing barriers to care and facilitating access to care.

In 2005, President Bush signed into law the Patient Navigator Outreach & Chronic Disease Prevention Program authorizing \$25 million dollars in grant funding to support prevention, screening and other outreach programs aimed at reducing health disparities. The funding guidelines for this program outlined six required responsibilities of all patient (non-medical) navigators participating in the program as follows:

- Acting as liaisons by assisting in the coordination of health care services and provider referrals.
- Facilitating the involvement of community organizations in assisting individuals who are at risk for or who have cancer or other chronic diseases to receive better access to high-quality health care services.
- Notifying individuals of clinical trials and, on request, facilitating enrollment of eligible individuals in these trials.
- Anticipating, identifying, and helping patients to overcome barriers within the health care system.
- Coordinating with the relevant health insurance ombudsman programs to provide information to individuals about health coverage.
- Conducting ongoing outreach to health disparity populations.¹⁶

In addition to the roles and responsibilities of patient navigators, different patient navigation models are employed at various settings such as community-based organizations and health clinics, cancer centers and hospitals. One program model can include navigators at each stage of

the cancer continuum, such as outreach and prevention, screening, diagnosis and treatment and post-treatment or survivorship care. A second model spans across the “entire continuum” with a patient navigator such as oncology nurse navigator guiding the patient throughout the process from suspicious finding to 12 months post-treatment.¹⁷ Other variation in models include the use of different types of navigators such as lay or peer navigators, social worker and nurse navigators or a combination thereof. Similar to the navigator, there is no one single patient navigation model as each is adopted and adapted to the community health needs and resources available.

Patient Navigators and Training

A wide array of patient navigation training programs exists across the country, though no national standard for training has yet been developed and instituted. The first training program for patient navigators was developed around the adult learning theory with the understanding that adults learn in various ways and through various channels.¹² The NCI and ACS 9-site demonstration project entitled, Patient Navigation Research Program (PNRP), centered on social cognitive theory that recognizes and addresses individual and structural determinants of health behavior to promote behavior change. The NCI-PNRP training, targeted to lay navigators, was a three-day in-person training that used a combination of lecture, interaction and role-play with case studies engaging instructors and participants. Key topics that were addressed at the training included: Overview of health Disparities/Cancer Disparities, Patient Navigation: Roles and Responsibilities, Overview of Cancer, Cancer Screening, and Cancer Treatment, Culture and Diversity, Communication, Introduction to Clinical Research and Mapping Resources. Evaluation of the training indicated that overall post-test scores improved compared to the pre-test scores (n=196) and greater education attainment and professional experience (high school education or greater or two years of experience or more) was a contributing factor. Though the training was targeted to lay navigators, trainees also included nurses, social workers and other health professionals.

Currently, patient navigation training programs vary in length, target audience, attendee requirement/pre-requisite, content focus and mode of delivery. A preliminary on-line search indicated that there are approximately 10 patient navigation training programs across seven (7) organizations in the U.S. Though the content focus of each training program can be applied to other chronic diseases such as heart disease, diabetes, and HIV/AIDS, the primary focus of each training program is centered on cancer. The training required to become a patient navigator is as varied as the navigators themselves. Some training programs include interactive classroom instruction while others are completely online or use a mixed-method approach. The length of programs can range from 160 class hours to six weeks to three days of instruction. There are basic skills programs that are targeted for all types of navigators such as lay, peer, social worker and nurse, while more advanced programs are specifically tailored to social worker and/or nurse navigators.

Common core competencies identified from these patient navigation training programs trainings include cancer care coordination and support services, education and support for cancer patients, families and caregivers, patient advocacy, health promotion and well-being, motivational interviewing, recognizing and alleviating stress and anxiety, psychosocial support, professional conduct (ethics) and the role of navigators in the context of the health care team. A standard training curriculum is needed to ensure that patient navigators have received basic skills and

knowledge in core competencies to perform their role as a patient navigator. More information on training programs and core competencies can be found in Appendix A.

Certifying the Patient Navigation Profession

With the varied roles and responsibilities, education and professional background, there are no uniform requirements for educational degree, professional experience or training that exists in patient navigation. The Northwest Regional Georgia Coalition (NRGC), the National Consortium of Breast Care Centers (NCBCC) and Sonoma State University (SSU) provide the closest representation to a certification program, though again the requirements are not standardized across the three programs. The NRGC offers two tracks, one for nurses and one for social workers, both with at least 1 year of experience. Both tracks are offered completely online and a test is required at the end of the course to demonstrate proficiency. NCBCC does not offer a formal training course, but administers a standardized test for breast patient navigators in imaging, and/or cancer. The duration of each test (imaging and cancer) is 2 hours and navigators must score 80% or higher to pass and receive certification. In the case of Sonoma State University, an accredited certificate program is offered by SSU that requires participants engage in 160 hours of class time and 50 hours of field work over the course of one (1) year as well as successfully navigate two (2) patients through observation to pass the course. The course is offered for registered nurses, clinical social workers, and licensed and non-licensed health professionals. However, there is no universal certification program and accreditation body for patient navigators. Once a standardized curriculum is agreed upon within the cancer community, concordance on designating an accreditation body would be the next step in establishing patient navigation as a recognized health care profession. Key stakeholders will also need to consider the role of an accrediting body for navigators assisting patients with non-cancer diseases (HIV, diabetes, etc.).

Demonstrating Patient Navigation's Value

In order for patient navigation to be solidified within the health care system infrastructure and funded, empirical evidence is needed to demonstrate the health benefit and cost-effectiveness of patient navigation. To demonstrate the value and policy implications of patient navigation in terms of both improvement in quality of life and monetary saving, it is necessary to evaluate the financial impact such as the cost-effectiveness and return on investment (ROI) of patient navigation. Whitley et. al. and others (Kreiger et. al., Fedder et. al.) have been successful in demonstrating the positive financial impact of community health workers using ROI.¹⁸ Despite these positive results, no consistent approach or method exists for evaluating either community health worker programs or patient navigation programs.

Results from small studies have shown that patient navigation has decreased time to diagnosis, reduced stress levels, increased patient satisfaction and improved care.¹⁷ The Henrico Doctor's Hospital breast cancer nurse navigation study echoed some of these benefits and also demonstrated an increase in patient retention that led to more billable services and greater total net revenue for the hospital. The study also indicated that time from suspicious finding to diagnosis was reduced from four (4) to two (2) weeks demonstrating the positive health and financial outcomes. Ramey et. al. identify challenges in the evaluation of patient navigation programs, such as the heterogeneity of the programs: no two programs are alike¹⁹ and the services that patient navigators provide are contingent on the needs of the patient which vary. In

addition, Ramsey et. al. states that qualification and training of navigators and supervisors also differ across settings which make standardized modeling difficult. The resolution of these issues will aid in establishing the value added of patient navigation to the health care system.

The NCI-PNRP and ACS-PNRP is a large scale effort to evaluate the time from screening to diagnosis and treatment and assess the impact of navigation on patient satisfaction and the cost-effectiveness of patient navigation programs.¹⁹ Results from this study will largely impact the patient navigation field in terms of patient navigation program design, effectiveness of patient navigation and efficacy as an intervention to reduce cancer health disparities. Preliminary results from PNRP presented at the American Association for Cancer Research's meeting on The Science of Health Disparities on September 18-20, 2011 reveal that the time required for navigated women to reach a definitive diagnosis following an abnormal screening was significantly shorter as compared to non-navigated women. Other federally funded programs include the Centers for Medicare and Medicaid six site demonstration project to study patient navigation²⁰ and the Health Resources and Services Administration patient navigation project which has funded 16 sites since 2008.^{21,22} Results of each of these projects are forthcoming.

Learning from the Community Health Worker Model

Across the country local, regional and state grassroots partnerships have emerged that have successfully integrated community health workers into the local and state health systems influencing the national agenda. An analysis into the creation and structure of these models will inform possible steps needed to integrate patient navigation into the national health system. Key themes identified across successful models from Alaska, Indiana, Texas, Minnesota and Massachusetts include: coalition building, standardized training curriculum, empirical evidence, advocacy and state and/or federal involvement (See Appendix B for descriptions).

In each of the CHW models researched, coalition building among service providers, local and state government, professionals and the community was a crucial element in establishing and promoting community health workers in the health care system. Coalitions such as the Community Health Worker Alliance in Minnesota and the Massachusetts Association of Community Health Workers successfully advocated at the state level to integrate community health workers into the health system using empirical evidence. For example, the Minnesota alliance made the case to the state legislature by demonstrating the ROI of paying for training and education of CHWs relative to the benefit to the community.²³ A Massachusetts study found that CHWs increased access to primary care through culturally competent outreach and improved the quality and cost-effectiveness of care through assisting patients with self-management of chronic disease. Standardized training was created in each of the states, though content, delivery and length of each training program continues to vary across state training programs. Typically, the accreditation body for the training program is housed at the state health department such as in Indiana and Texas. Financing for CHWs come from various sources. In Alaska, salaries and benefits of CHWs are paid by the corporations that employ them. However, in Massachusetts, funding for CHWs comes from the state budget. Of the five states, Minnesota and Indiana have been successful in obtaining reimbursable services under Medicaid for CHWs who work under the supervision of approved Medicaid billers such as advanced practice nurses, physicians, dentists, public health nurses and mental health providers. This brief analysis of the path that the states of Alaska, Indiana, Texas, Massachusetts and Minnesota took to incorporate community

health workers into the local and state health systems can inform patient navigation's establishment as a recognized health profession. Critical to the process are the convening of stakeholders, development of training programs, occupational regulation, patient navigation workforce assessment and advocacy for policy and health care system and delivery change.

Moving the Conversation Forward

With the passage of the Patient Protection and Affordable Care Act in 2010, anticipated outcomes from the NCI-PNRP and ACS-PNP and projected oncology workforce shortage, now is a critical time to begin the process of integrating patient navigation as a sustainable service into the health care system. To address this significant effort, GWCI, ACS and UIC partnered to host a national patient navigation meeting in Washington, D.C. to create buy-in and consensus on a phased approach and strategic plan to collectively tackle the challenges in patient navigation, mentioned above, through a formalized consortium of leaders and experts in patient navigation. The meeting will bring together stakeholders from academia, research, community and clinical settings, advocacy and policy. Initiatives coming out of this meeting may include curriculum development and training and accreditation standards and will likely require a multi-year, multi-stakeholder and multi-funder approach. By unifying as a group, rather than working as individual organizations, we are better able to leverage one another's strengths and influence the national agenda to achieve the ultimate goal of sustaining patient navigation within the health care system to reduce health disparities and improve quality of life not just for cancer patients, but for those who suffer from a multitude of chronic diseases.

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Appendix B: Meeting Agenda

NATIONAL PATIENT NAVIGATION COLLABORATIVE MEETING AGENDA

DECEMBER 9, 2011

GW CLOYD HECK MARVIN CENTER, ROOM 310

800 21 ST NW, WASHINGTON, DC 20052

The goal of the Collaborative is to develop a strategic plan to support the development of patient navigation as an integral part of the health care system.

Meeting Objectives:

- 1) Discuss successful strategies used in other health professions to establish standardized core competencies for training programs,
- 2) Develop and seek agreement on a phased plan to meet the NPNC goal, and
- 3) Devise an approach for implementing the strategic plan through NPNC workgroups focusing first on training and credentialing.

December 9, 2011

8:00 a.m. – 8:30 a.m.

Breakfast

8:30 a.m. – 9:00 a.m.

Introductions and Welcome

Steven R. Patierno, PhD, GW Cancer Institute
Angelina Esparza, RN, MPH, American Cancer Society
Beth Calhoun, PhD, University of Illinois at Chicago

9:00 a.m. – 9:15 a.m.

Framework for Developing Patient Navigation as Part of the Health care Workforce

Presenter: Rebecca Kirch, American Cancer Society

9:15 a.m. – 9:45 a.m.

Strategies for Developing a National Training Curriculum **Learning from the Community Health Worker Models**

Presenters: Anne Willaert, South Central College, Minnesota
Community Health Worker Alliance

Ron Cookston, EdD, Gateway to Care

Discuss the main challenges and strategies used to advance the community health worker field that can be applied to patient navigation.

9:45 a.m. -10:30 a.m.

Navigator Training Models

Presenters: Harold P. Freeman, MD, Harold P. Freeman Patient Navigation Institute, Ralph Lauren Center for Cancer Care and Prevention

Elizabeth Whitley, PhD, RN, Denver Health Community Voices, Colorado Patient Navigation Training, Denver PNRP

Steven R. Patierno, PhD, GW Cancer Institute

An overview of patient navigation training models from New York, Denver, and Washington, DC.

- 10:30 a.m. – 10:45 a.m. Coffee Break**
- 10:45 a.m. – 12:15 p.m. Moving Towards a Strategic Plan**
 Facilitators: Steven R. Patierno, Beth Calhoun
Develop a short-, intermediate- and long-term plan for training and certification.
- *Roles of consortium members*
 - *Defining the curriculum (core components, tracks, etc.)*
 - *Establishing base core elements for all training programs*
- 12:15 p.m. – 1:00 p.m. Lunch**
- 1:00 p.m. – 2:00 p.m. Measuring Progress**
 Facilitators: Beth Calhoun, Rebecca Kirch
Identify short and long-term goals, timelines and measures of success of the plan.
- 2:00 p.m. – 3:00 p.m. Next Steps: Implementing Strategic Plan**
 Facilitator: Angelina Esparza
Identifying action steps to develop consortium.
Discussion of potential working groups post-meeting.
- 3:00 p.m. – 3:30 p.m. Wrap-Up and Adjourn**
 Mandi Pratt-Chapman, MA, GW Cancer Institute

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Appendix C: Attendee List

Tracy Battaglia, MD, MPH

*Associate Professor of Medicine and
Epidemiology, Associate Program
Director, Preventive Medicine
Residency Program
Boston University*

Jennifer Bires, LICSW

*Member, Association of
Oncology Social Work,
Hematology/Oncology Social Worker
GW Medical Faculty Associates*

Jennifer Bretsch, MS

*Program Manager,
Division of Cancer Survivorship
GW Cancer Institute*

Elizabeth Calhoun, PhD

*Professor of Health Policy and
Administration
University of Illinois at Chicago*

Christina Cianflone, JD

*Director, Cancer Prevention and
Community Health
GW Cancer Institute*

Elizabeth Clark, PhD, ACSW, MPH

*Executive Director
National Association of Social Workers*

Ron Cookston, EdD

*Executive Director
Gateway to Care*

Chris Dammert

*Director, Navigation Services
LIVESTRONG*

Andrea Dwyer, MPH

*Project Director, Cancer Prevention and
Control Research Network
University of Colorado at Denver*

Angelina Esparza, RN, MPH

*Director of Health Equity
American Cancer Society*

**Elizabeth Evans, RN, BSN, MPM, CPHQ,
CPHIMS, FACMPE**

*Executive Director of Professional
Practice and Programs
Oncology Nursing Society*

Heidi Floden, PharmD

*Board Member, Association of
Community Cancer Centers,
Director, Hematology/Oncology &
Pharmacy Services
GW Medical Faculty Associates*

Sharon Francz, LPN, BSHA

*President and Co-Founder
National Coalition of Oncology
Nurse Navigators*

Harold P. Freeman, MD

*President and Founder
Harold P. Freeman Patient Navigation
Institute/Ralph Lauren Center for
Cancer Care and Prevention*

Sharon Gentry, RN, MSN, AOCN, CBNC

*Leadership Council, Academy of
Oncology Nurse Navigators,
Breast Nurse Navigator
Derrick L. Davis Forsyth Regional
Cancer Center*

Kristi Gullory, JD

*Senior Policy Analyst
American Cancer Society
Cancer Action Network*

Elizabeth Hatcher, BSN, RN

*Special Projects Coordinator,
Division of Cancer Survivorship
GW Cancer Institute*

Sarah Hijaz, MPH

*Program Coordinator, Geographic
Management Program
GW Cancer Institute*

Lovell Jones, PhD

*Director, Center for Research on
Minority Health Department of Health
Disparities Research
University of Texas M.D Anderson
Cancer Center*

Rebecca Kirch

*Director of Quality of Life and
Survivorship, Cancer Control
American Cancer Society*

Paul Klintworth, MSPM

*Project Manager, DC City-wide Patient
Navigation Network
GW Cancer Institute*

Michelle Y. Martin, PhD
*Associate Professor of Medicine,
Division of Preventive Medicine*
University of Alabama at Birmingham

Dearell Niemeyer, MPH
*Managing Director, Mission Delivery
Services & Initiatives*
American Cancer Society

Steven R. Patierno, PhD
Executive Director
GW Cancer Institute

Mandi Pratt-Chapman, MA
*Associate Director,
Community Programs*
GW Cancer Institute

Elisabeth Reed
*Program Coordinator,
Division of Cancer Survivorship*
GW Cancer Institute

Betsy Risendal, PhD
*Director/Principal Investigator,
Colorado Patient Navigation Training*
University of Colorado Denver

Rian Rodriguez, MPH
Research Manager
Harold P. Freeman Patient
Navigation Institute

Jean Sellers, RN
*Administrative Director, UNC
Lineberger's Cancer Outreach Program*
University of North Carolina

Mona Shah, MPH
Associate Director of Federal Relations
American Cancer Society
Cancer Action Network

Melissa Sileo, MSW, LCSW
Senior Manager of Navigation Services
LIVESTRONG

Virginia Vaitones, MSW, OSW-C
*Member, Commission on Cancer
Oncology Social Worker*
Penobscot Bay Medical Center

Patricia Valverde, MPH
*Associate Director, Colorado Patient
Navigator Training*
University of Colorado Denver

Liz Whitley, PhD, RN
*Director, Denver Health Community
Voices*
Co-Principal Investigator
Colorado Patient Navigation Training
and Denver PNRP

Anne Willaert
Grants/Special Projects Director
South Central College
Minnesota Community Health
Worker Alliance

Anne Willis, MA
Director, Division of Cancer Survivorship
GW Cancer Institute

Appendix D: List of Acronyms

ACA – Affordable Care Act

ACCC – Association of Community Cancer Centers

ACS – American Cancer Society

caSNP – Center for the Advancement of Cancer Survivorship, Navigation and Policy

CHW – Community Health Worker

CMMI – Center for Medicare and Medicaid Innovation

CMS – Centers for Medicare and Medicaid

CoC – Commission on Cancer

FQHC – Federally Qualified Health Center

GTC – Gateway to Care

GWCI – George Washington Cancer Institute

HHS – Department of Health and Human Services

IOM – Institute of Medicine

NASW – National Association of Social Workers

NPNC – National Patient Navigation Collaborative

ONS - Oncology Nursing Society

PNRP – Patient Navigation Research Program

UIC – University of Illinois at Chicago