

THE **DRA** Accelerating Disparity  
Reducing Advances  
**PROJECT**



**Report of the Enhanced Consumer Navigation Support  
Committee**

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# Report of the Enhanced Consumer Navigation Support Committee

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## Introduction

Ensuring that underserved patients have the support they need to navigate our complex healthcare system is an important for reducing health disparities. There are a number of advances that could improve the quality of consumer navigational support over the next ten years. These advances include both electronic and personal navigators. Organizations such as the National Cancer Institute and the American Cancer Society have significant experience with Navigator Programs. Related activities include:

- Patient Navigators to help underserved patients overcome barriers in the healthcare system.
- Patient Advocates that work on behalf of patients to improve the healthcare system and troubleshoot problems.
- Community Health Workers that work to integrate information about health and the health care system into underserved communities
- Lay Health Advocates that serve as an interface between the congregations of local churches and the healthcare system

## Patient Navigators and Advocates

Patient navigators help patients and their families navigate the fragmented maze of doctors' offices, clinics, hospitals, out-patient centers, payment systems, support organizations and other components of the healthcare system. Navigation services include:

- Facilitating communication among patients, family members, survivors and healthcare providers.
- Coordinating care among providers.
- Arranging financial support and assisting with paperwork.
- Arranging transportation and child care.
- Ensuring that appropriate medical records are available at medical appointments.
- Facilitating follow-up appointments.
- Community outreach and building partnership with local agencies and groups.
- Ensuring access to clinical trials.<sup>1</sup>

Patient Navigator programs range from trained volunteers who use the telephone to help patients navigate the healthcare system to trained nurse practitioners who worked in person with patients. While there is no set education required for a patient navigator to be successful, a successful navigator should be:

- Compassionate, sensitive, culturally attuned to the people and community being served and able to communicate effectively.
- Knowledgeable about the environment and healthcare system.
- Connected with critical decision makers inside the system, especially financial decision makers.<sup>2</sup>

Patient navigators and advocates are similar in many respects. Like patient navigators, patient advocates assist patients by interacting with the healthcare system on the patient's behalf and troubleshooting problems as they arise. A distinction between the two can be drawn due to the focus of these two groups. Unlike, navigators, the concern of patient advocates look to improve the system as a whole, rather than the delivery of care to individual patients.<sup>3</sup> In this sense, patient advocates can include healthcare providers, volunteer activists and advocacy groups who work to advocate for change on behalf of patients.

## Community Health Workers

Community health workers are community members that work inside the community as connectors between health care consumers and providers. They serve as interfaces between underserved communities and the healthcare system. Community health workers help patients access the services they need and are important in stimulating community participation in health related activities (e.g. screening programs, health/wellness programs, health education, ect.). Community health workers are also known as community health advisors, lay health advocates and promotores de salud.<sup>4</sup>

There are some distinctions between these different types of community health workers. For example, lay health advocates often serve as connections between a church congregation and the medical system. Depending on one's perspective, promotores de salud can refer to a subset of community health workers inside Latino communities or an alternate approach that comes more from a social model of care rather than a medical model. Promotores (without "de salud") can also refer to those who provide broader social services inside the community.<sup>5</sup> The key roles of most community health workers include:

- Serving as interfaces between communities and the health care system.
- Providing culturally appropriate and accessible health education and information.
- Assuring that people get the services they need.
- Providing informal counseling and social support.
- Advocating for individuals and communities.
- Providing direct services (such as basic first aid)
- Administering health screening tests.
- Building individual and community capacity.<sup>6</sup>

It is important to note that community health workers are not a new phenomenon. All of the world's cultures have had community members that the community has turned to for support and advice. In the United States, trained workers have been acting in this role since at least the 1950s. A national study of community health advisors estimated there were more than 600 programs with more than 12,500 community health workers nationwide. It is estimated that one fourth of these community health workers are volunteers.<sup>7</sup>

## Electronic Navigation

Another opportunity to improve consumer navigation of the healthcare system is through electronic navigation. This includes tools for finding healthcare resources and managing healthcare records. This kind of electronic navigation support is becoming more common inside companies as they switch to more consumer directed care models for their employees. These portals offer tools for submitting and tracking claims as well as accessing health information, health savings accounts, flexible spending accounts, prescription drug comparisons, hospital comparisons and other tools to help patients navigate the healthcare system. Some examples of companies offering these solutions to companies and individuals:

- Connect Your Care, a subsidiary of the Revolution Health Group Company, offers a one stop portal for consumers inside companies. Through the portal, they can access plan information, submit and track claims. They can also access a wide variety of health and wellness information and tools for comparing providers and medications.<sup>8</sup>
- Benefitfocus offers a consumer directed healthcare portal that includes claims tracking and health information. The portal also has a language translation system that allows consumer navigation in a wide range of languages and dialects.<sup>9</sup>
- Health management firm, SHPS, plans to launch in late 2006 a healthcare portal that provides a one stop shop for patients to enroll and track benefits, manage their health and evaluate physicians and hospitals.<sup>10</sup>

These healthcare portals are designed and targeted for large employers implementing consumer directed care plans. However, there is an opportunity to use the learning from these systems as they roll out to develop similar products to help underserved populations navigate the healthcare system. These products would need to be culturally and linguistically appropriate for different target populations. The systems would also need to focus much more on public services available for low income patients. For many populations, access and experience with using information technology will also need to affect the design of these systems. This might indicate different platforms for delivery of the information such as using cell phones rather than computers.

## Recent Developments

A number of patient navigator programs are already underway or recently completed to reduce health disparities. A survey conducted by the National Cancer Institute in 2003 found more than 200 cancer programs nationwide with some form of patient navigation. Most of these were funded by small grants from foundations.<sup>11</sup> Some of the more significant programs include:

**Center to Reduce Cancer Health Disparities (CRCHD):** The CRCHD is running a Patient Navigator Program designed to reduce disparities in cancer care. The gap between a cancer discovery and the delivery of cancer care leads to disparities in outcomes. Started in 2002, the Patient Navigator Program has three research projects to evaluate the efficacy and cost-effectiveness of patient navigation. The primary project is providing five year funding to eight

project sites looking at four types of cancer (breast, cervical, colorectal and prostate) and a range of underserved populations.<sup>12</sup>

**Cancer Care Nova Scotia:** In 2002, Nova Scotia began a patient navigator program for cancer in three early adopter sites. Peer review of the program in 2004 found that patient navigators significantly benefited cancer patients and their families in dealing with the emotional turmoil, informational needs and logistical challenges associated with having cancer. It resulted in more efficient use of clinical time of physicians and more appropriate use of community health professionals.<sup>13</sup>

**Centers for Medicare and Medicaid Services (CMS):** In March of 2006, CMS announced a program to provide patient navigators to 13,000 minority patients. The program targets breast, cervical, colorectal and prostate cancer in a variety of minority populations. Researchers will study whether patient navigators improve care for minorities. The program will cost almost \$24 million and last four years.

**American Cancer Society (ACS):** The ACS introduced the first patient navigator program for cancer at Harlem Hospital in 1990. The ACS continues to support patient navigator programs throughout the United States as well as supporting recent legislation for federally funded patient navigation.

## Recent Research

Outcomes research for patient navigator programs is relatively scarce for two reasons. The first reason is that many of the systematic evaluation of patient navigation programs, such as the CRCHD Patient Navigator Program, are still underway. The other barrier is a lack of a clear definition for patient navigation. Without a clear definition it is difficult for researchers to separate patient navigation from other care support services and compare existing programs. To a certain extent, this is due to the very nature of patient navigators. At their best, patient navigators overcome barriers to care and solve problems for their patients. These activities can encompass a wide variety of services and functions, making one static definition based on services provided difficult. A definition for patient navigators that focuses on their ability to address barriers to care may be more useful for research and evaluation.<sup>14</sup>

There are a number of promising studies of navigation programs that show promising outcomes:

- Studies at Harlem Hospital comparing a 22 year period ending in 1986 with a five year period from 1995 to 2000 showed a jump in five year survival rates for breast cancer from 39% to 70%. The ACS Patient Navigation program is believed to be a critical component of this increase.<sup>15</sup>
- A study at a large urban public hospital indicates that patient navigators could increase the likelihood of a patient keeping an appointment for colonoscopy three fold.<sup>16</sup>
- A study of low income women in New York found increased rates of cancer screening when the women were contacted by phone with a trained navigator.<sup>17</sup> The program was run by the Clinic Directors Network and supported by the American Cancer Society.

Empirical research on the effectiveness of community health workers is also limited. The majority of research on community health workers has attempted to quantify the impact of community health workers on patient satisfaction, health knowledge, service utilization, and health status. Studies on the cost effectiveness of community health workers are not available. The research suggests that community health workers are effective in:

- Increasing health related knowledge and self-care practices through education.
- Encouraging behavior change by providing support, encouragement and serving as role models.
- Improving follow-up of medical care by improving case management tracking and monitoring patients.
- Providing high value services not only for clients, but also for healthcare providers.
- Decreasing high risk behaviors in underserved communities.
- Increasing screening rates for disease in underserved communities.<sup>18</sup>

## DRA Project Opportunities for Reducing Health Disparities

A number of opportunities exist to improve existing navigator programs. The most important, and most audacious, is to streamline the existing healthcare system so navigation is easier for both patients and providers. This is the root cause of the problem, and one that should be addressed directly. Other opportunities that the DRA Project might support include:

- Developing simple and clear documentation in health systems.
- Developing some common definitions for health navigators and health navigator programs.
- Identifying and supporting ongoing sources of payment for consumer navigation.
- Identify and disseminate best practices for health navigators.
- Develop a website that will act as a resource for existing navigators, especially lay navigators, to access best practices.
- Develop and distribute to the navigator community forecasts for key emerging technologies and health care practices that are relevant to the navigator function
- Research/explore how to integrate information/knowledge technology with the working practices of navigators.
- Research/develop a “health compass” for individuals to help them manage the healthcare system.

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