CANCER PATIENT NAVIGATION PROGRAM TOOLKIT

Kansas Cancer Partnership

KANSAS
comprehensive cancer | control & prevention

Comprehensive Cancer Control is an integrated and coordinated approach to reducing cancer incidence, morbidity and mortality through prevention, early detection, treatment, rehabilitation and palliation.

Mission: Protecting the health and environment of all Kansans by promoting responsible choices.

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Introduction

In 2003, the state of Kansas was charged with developing a comprehensive plan to address the burden of cancer. The Kansas Comprehensive Cancer Control (CCC) and Prevention Plan was published in March 2005, a culmination of 18 months of work by a core group of dedicated partners. This group approached the problem of cancer from four aspects: prevention, screening/diagnosis, treatment and survivorship/end-of-life. Since its publication, the Kansas Cancer Partnership has grown to more than 180 individuals representing public and private entities across the state who are interested in addressing the problem of cancer.

The Partnership began implementation of the Plan and is working in the areas of patient navigation/access to care, policy/advocacy, professional education, public education, research/data and survivorship/end-of-life.

Of particular interest in this document is the area of patient navigation for those diagnosed with cancer. Patient navigation has different meanings for different people. In this workbook, readers are presented with a definition of patient navigation and the tools and information needed to establish or implement a Patient Navigation Program in their health care system.

Problem Statement

Patient navigation is a vague phrase. Members of the Partnership identified the basic need as, "Patient Navigators are needed to assist with cancer care."

If you ask people if they know what the phrase **patient navigation** means, many would be unable to tell you. Others believe the term is synonymous with case management or patient advocacy. For the purposes of this document patient navigation is used as a comprehensive term to describe "the type of care afforded to people from the time their cancer is diagnosed, through testing, surgery, radiation, chemotherapy, survivorship or end-of-life care." In other words, a Patient Navigation Program would provide a means for cancer patients to "navigate" their way through the health care system.

Cancer patients and their families deserve quality care and services as they fight their disease. Patient navigation services can provide individualized support, care coordination, empowerment and advocacy to assure patients' needs are met. Patients often need one "contact" person or an identifiable team they can call when they have a problem or identify a need.

As a health care provider you and your organization strive to provide quality patient care and treatment. Exploring the idea of a patient navigation system and establishing that system in your organization may provide cancer patients with the tools they need to fight their cancer.

Kansas CCC Patient Navigator Definition

Patient Navigators wear many hats and play critical roles in patients' cancer care. The Kansas Cancer Partnership's Patient Navigator/Access to Care Workgroup established the following definition of Patient Navigators: "Patient navigators are health care professionals whose primary focus is to assist cancer patients, caregivers and families in 'bridging the gaps' within the health care system and decreasing barriers to care by utilizing resources.

With a nursing background, Navigators become the central point of contact for coordinating communication with all team members and ensure that cancer patients receive quality cancer care. Navigators facilitate interaction and communication with cancer patients, caregivers and family members, and have the appropriate skills and access within their organizations to provide education related to cancer treatments, pathology, palliative care and resources."

The Navigator serves as a link to available resources for the patient. These resources include: connecting patients to social support services that require finding ways to pay for care, providing education and educational resources, and assisting with transportation, support groups and other areas of psychosocial needs.

A Patient Navigator guides patients through the health care system, improves the quality of their care, and extends or even saves lives. The Navigator fills the following key roles:

1) Service to the Patient
2) Coordination of Care
3) Follow-up and Support

Additional information about establishing and implementing a Patient Navigator Program can be obtained at www.cancerkansas.org .
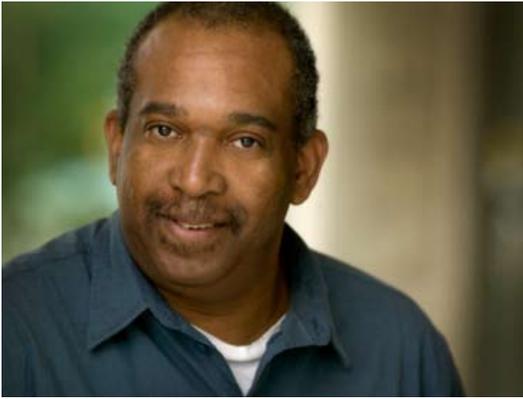
Background

Dr. Harold Freeman is referred to as the founder of patient navigation. He recognized the need to decrease health care inequities and delays in follow-up cancer care at Harlem Hospital in New York in 1989. He described patient navigation as a means for improving access to recommended cancer screening services, follow-up, diagnosis, and treatment in medically underserved populations.

The U.S. President's Cancer Panel report, *Voices of a Broken System*, was issued in 2001. The report indicated that barriers to cancer care were not limited to the poor, but encompassed all socioeconomic levels. One of the recommendations of the report was to support Patient Navigation Programs.

In June 2005 the Patient Navigator, Outreach and Chronic Disease Prevention Act was signed into federal law. This law recognizes the challenges patients face in getting the health care they need and focuses federal resources to establish patient navigation services.

As Americans continue to live longer, more and more will be diagnosed with cancer. With advances in early screening and detection and advanced methods of treatment, cancer becomes a more survivable disease. This underscores the need for patient navigation as cancer patients become cancer survivors.

Kansas Cancer Centers Survey

Background

The Comprehensive Cancer Control and Prevention Plan, published in March 2005, identified patient navigation as one of the objectives that would help improve the survivorship for cancer patients. The Plan indicates an overall goal to "improve communication for patients and providers, including developing a medical advocacy program." The Plan further strives to address the "need for better communication and coordination between health care team members including primary care physicians, generalists, internists, surgeons, clinical oncologists and radiation oncologists." The Plan states: "Every cancer patient will be provided the opportunity to have a Patient Navigator or advocate assisting in his/her continuum of care."

Based on these objectives and in order to gather baseline data to identify the problem, in March 2006 the Kansas Cancer Partnership invited 57 Cancer Centers, identified as providing cancer patient services across the state of Kansas, to complete a survey to help identify needs, gaps and barriers to quality services in the state. The survey focused on gathering information about patient services pertinent to those affected by cancer as they navigate their way through the health care system. The goal of the survey was to assess the need for establishing Patient Navigator Programs in health care centers statewide.

The survey data was gathered in the spring of 2006, analyzed throughout the summer, and culminated in a draft document that was reviewed by the Kansas Cancer Partnership's Patient Navigator Workgroup in September 2006. A total of 41 Centers returned the completed survey (72% response rate). The objectives of the survey were to:

- Assess the level of coverage of cancer diagnosis and treatment services in Kansas,
- Identify strengths and weaknesses of the current cancer care delivery system,
- Inform the cancer centers about existing services, and
- Generate pertinent information that could support a Patient Navigation Program in Kansas in the future.

Methodology

Several means were used to administer the 26-question survey. A comprehensive list of Cancer Centers was researched and generated by the Partnership along with contact names, addresses and other pertinent information. The Kansas Cancer Partnership's Patient Navigator Workgroup identified a number of issues that were used to craft questions for the survey. A letter was sent to a contact person of each Center to invite him or her to participate in the survey by either filling out a Web based electronic copy online or a hard copy (pencil-and-paper type) to be returned by mail. Follow-up phone calls were made if no response was received after a month. The completed mail-in surveys were converted into electronic format. The data was analyzed using a SAS statistical package. The following is a summary of the results gathered from the responses.

Access to Patient Navigation Program

Participants were asked if their facility provided patient navigator services to cancer patients. For the purpose of this survey Patient Navigators were described as health professionals who work with patients, their families and their providers to ensure that their needs are effectively addressed. To that question, 68.3% of centers said yes, 26.8% said no and 4.9% were unsure or did not know if their facility provided patient navigation services.

Does your facility provide patient navigator services to cancer patients?
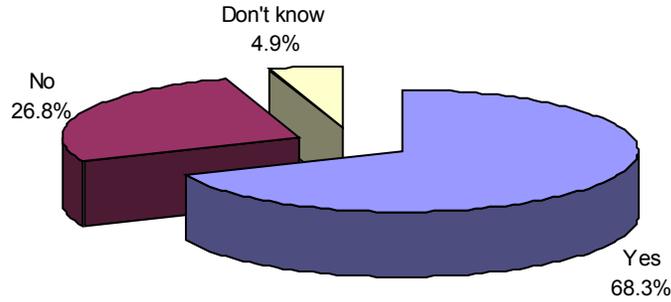

Those who reported that their facility provided patient navigator services to cancer patients were further asked about the qualifications of the Patient Navigators. Eighteen (18) centers (43.9%) reported their navigators were social workers, 22 (53.7%) reported their navigators were nurses, eight (19.5%) reported their navigators were lay health workers and nine (22%) reported other types of professionals as being responsible for patient navigation at their facility. Those professionals included Utilization Review Nurses, physicians, financial counselors and billing clerks.

Types of Personnel Responsible for Patient Navigation at the Surveyed Cancer Centers
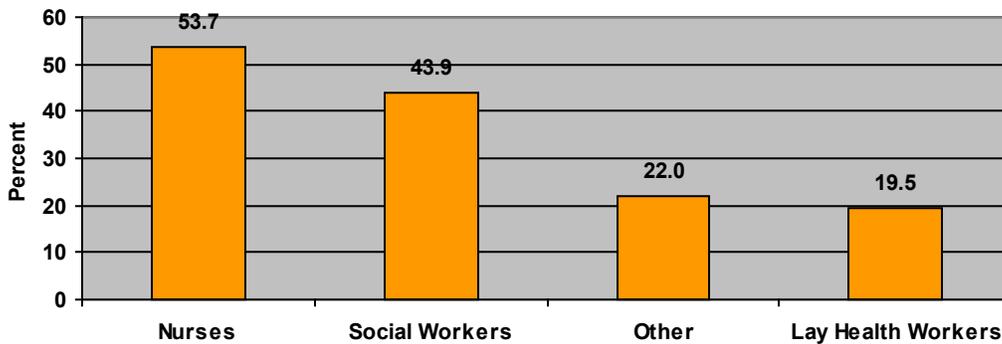
Those who reported having patient navigation services at their facility also were asked about the employment status of the current Patient Navigators. To that question, 83.3% of respondents reported their Patient Navigators were employees of the facility. None responded that they were completely volunteers, 6.7% reported that they were partly paid staff and partly volunteer staff, and 10% said they do not have patient navigator roles at their facility.

Employment Status of Patient Navigators, As Reported by Survey Participants

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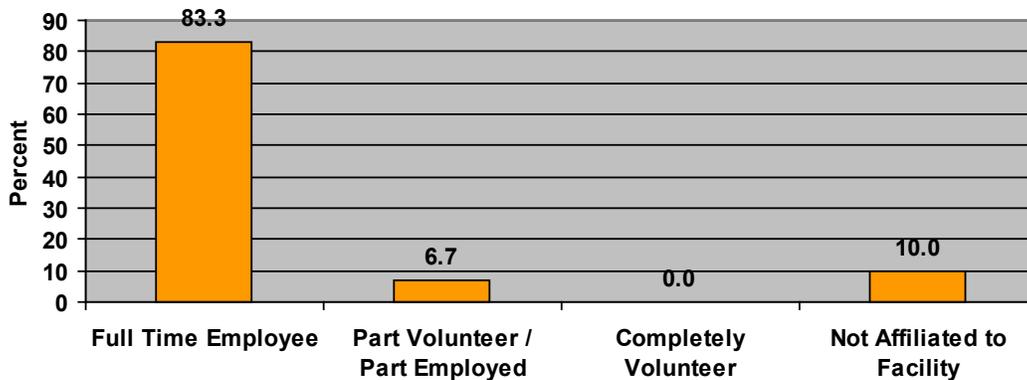
Listen and Learn with Kansas Cancer Patients and Families

In addition to the survey of the Kansas Cancer Centers, the Partnership was interested in hearing directly from cancer survivors and their families about their experiences living with cancer. The Kansas LIFE Project, working in conjunction with the Partnership, engaged Kansas cancer patients and caregivers in a process called "Listen and Learn." During this process cancer survivors shared their experiences within the health care system from diagnosis through treatment and into post-care. Information was collected to help in the development of future patient navigation, advocacy and other projects related to the state Comprehensive Cancer Control Plan and designed to best support and serve Kansas cancer patients and caregivers.

Fifty-two (52) Kansas cancer patients and caregivers participated in six focus group meetings held in Wichita, Salina, Phillipsburg and Lawrence. The six groups met in April and May of 2006. In each focus group, an identical set of questions was used to garner feedback and to listen to and learn from their experiences. The feedback from these sessions provided a comprehensive look at how individuals with cancer are living with the disease and their individual experiences.

Key messages that emerged from Listen and Learn include:

Kansas cancer patients and caregivers must serve as their own advocates throughout the process of receiving care.
Over and over, survivors told stories of needing information and working to find this information themselves. Cancer survivors who felt most empowered repeated the need to seek information, ask questions and be actively engaged in their own care plans.

Support groups are critical sources of information, coping and support for Kansas cancer patients and caregivers.
Participants often shared how important the support group relationships have been for them. In the support group they find others who really understand what they are dealing with, links to resources and a continuing place to share openly.

Healthcare providers who talk openly with patients, help them understand their choices and honor their choices, are important in overall quality of care.
Participants expressed genuine appreciation with physicians' offices and staff who shared honestly and openly with them. Though fears and anxieties persist, having healthcare providers who pay attention to individuals' needs adds a lot to the quality of care as perceived by patients and families.

Waiting for tests results is a major source of anxiety. When and how patients are informed is of great importance to patients and families.
In almost every group, patients shared their anxieties about waiting for test results. They had concerns about what and how they were told. Several discussed being told they would be called the next day and then having to wait over a long weekend before learning anything. Specific details for when results will be known and telling patients how they will be informed can help.

Key Recommendations from the Listen and Learn Group Participants include:

Provide Kansas cancer patients and caregivers with information and support to serve as their own advocates.
Survivors and caregivers often feel unsure about or feel unable to:
- identify where and how to get the best information,
- identify what to expect in their care,
- understand and interpret choices in care,
- know what to do with unanswered questions,
- express their healthcare choices, and receive care that they feel best meets their needs.

Materials which describe what to expect, how to get answers to questions, and how to locate support groups and find additional information are critically important. Attention given to centralized resources where critical and consistent information is available to all cancer patients is important. A statewide website (established 9/2006) will help address these needs. While many resources address numerous issues and needs, it is important that information on the web covers issues of importance to Kansans. The items bulleted above are the key issues discussed by participants in these groups.

Assure that support groups are available and easily accessible to all Kansas cancer patients and families.
While cancer patients often find support groups are important to living with cancer, some Kansas cancer patients report they were not informed about support groups. Others report that the support groups that they found consisted of people of different ages or with very different interests than theirs. Identification of support groups in every county of Kansas is important and should be easily available to all Kansans. For minimal cost, staff could be assigned the task of locating key resources within each county and including this information in a centralized website. Follow-up staff time would be needed to update the information annually.

Provide and demonstrate the value to patients of a patient advocate to help patients understand their conditions and needs, understand their choices in care, express their choices and have their choices honored.
Consistent across all the focus groups was the need for help in understanding medical issues, making good choices, receiving best care and working through a variety of issues. Kansas can implement a project to provide advocacy services and improve patient satisfaction. From this demonstration, further action steps may be determined. A pilot project in patient advocacy and navigation could address many patient concerns and improve patient satisfaction and quality of life. While many Kansans share how helpful their healthcare providers are, others do not feel that they are helped by their providers. Patients often feel that their providers are too busy or that the providers deal with only the physical issues, leaving them to fend for the other needs that are often unmet. A direct patient advocate may bridge this gap. A pilot project that provides mentors could be explored. Several participants mentioned the idea of having a mentor—a cancer survivor—to befriend them.

Provide focused education to Kansas healthcare providers that stresses key components of good communication with patients, breaking bad news, and understanding issues and needs faced by cancer patients.
The state can encourage provider groups and associations to assure this education is provided to their members. Key modules of teaching and an expert faculty can be developed and made available to provider groups. Groups that offer these educational programs can be publicly recognized and thanked. Licensing groups could be asked to provide critical information to those they license and to encourage better awareness of needs of cancer patients and families.

Provide leadership to raise the bar in support of patient advocacy, high expectations for the quality of life, and providing information and resources to patients.
In addition to a website and possible access to a statewide call-in phone number, patients need to have easy access to these resources when they are needed. A public and provider engagement campaign could draw attention to

resources, and simple materials can be created that will promote the number and website to Kansas cancer patients and their families. Working with existing community action groups, a pilot project in an urban, rural and mixed community can demonstrate the effectiveness of grassroots activism in informing and supporting Kansans with cancer. Basic informational materials may be placed in libraries, faith communities, senior centers, pharmacies, physicians' offices, cancer centers, etc. Key information can also go to each physician, nurse and social worker by engaging and working with licensing boards.

Provide employer education to better meet needs of Kansans.
While some participants felt supported by their employers, others did not. Some worked hard to make their illness a non-issue. Working with employers can strengthen their support of the cancer patient and also assist coworkers in supporting the cancer patient.

Summary of Listen and Learn:

The Listen and Learn information has provided critical direction for implementing the Kansas Cancer Plan. A number of needs are already being addressed in areas including: website establishment; Patient Navigation Program pilot; cancer patient screening tool development; and employer training and education for health care providers. For more information about the progress made by the Kansas Cancer Partnership and other helpful information refer to the Resources section of this document.

Implementing a Patient Navigator Program

Step 1: Assess need for implementation of Patient Navigator Program

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Step 2: Enlist support from departments/organizations involved in the care of patients

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Step 3A: Evaluate potential obstacles to implementation and consider opportunities and alternatives → **Step 3B**: Determine program scope, cost and implementation strategy

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Step 4: Implement Patient Navigator Program

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Identify Patient Navigator

Coordinate program planning with appropriate departments and organizations.	Prepare documents: posters, brochures, policies, procedures, forms, etc.	Implement support systems, referral processes, outreach strategies, etc.	Track responses, appointments, and other relevant data.

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Step 5: Assess program effectiveness

Additional Resources for Cancer Patient Navigation

- C-Change, Collaborating to Conquer Cancer. Cancer Patient Navigation: Care for your Community. A guide to community navigation. www.cancerpatientnavigation.org

- *Cultural Competence in Cancer Care: A Health Care Professional's Passport* is a tool that will assist primary care physicians and other health care professionals in their efforts to reduce and eliminate cancer health disparities by providing them with information about the relationship between cancer and culture, the most prevalent cancers in certain minority groups, cultural and behavioral characteristics within each of these groups, and strategies that health care professionals can use in an effort to decrease health disparities in cancer care. *Matthews-Juarez, Pat, and Weinberg, Armin. Cultural Competence in Cancer Care: A Health Care Professional's Passport.* Intercultural Cancer Council*, 2006.* http://iccnetwork.org

- *The Cancer Survival Toolbox* ® is a joint project between the National Coalition for Cancer Survivorship (NCCS), the National Association of Social Workers, the Association of Oncology Social Work and the Oncology Nursing Society. It is a free, self-learning audio resource program for people diagnosed with cancer and their families. This award-winning self-advocacy program helps people develop skills to better meet and understand the challenges of their illness. One of the most recent modules in the *Toolbox* will focus on patient navigation. www.cancersurvivaltoolbox.org

- Pfizer and the Healthcare Association of New York State developed a *Cancer Patient Navigation Toolkit* (for hospital-based cancer programs); includes implementation and training guides for the program champion and resource guides for the patient navigator. www.patientnavigation.com

- National Patient Advocate Foundation (NPAF) is a national, non-profit organization that is dedicated to the mission of creating avenues of patient access through improved access to, and reimbursement for, evolving therapies, therapeutic agents, and devices through policy and legislative reform at the state and federal levels. The NPAF mission is shaped by the experiences of the patients served through their companion organization, Patient Advocate Foundation. http://www.npaf.org

Frequently Asked Questions (FAQs) for Cancer Patient Navigation (CPN) Programs

1. What is cancer patient navigation?

Patient navigation in cancer care refers to individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality medical and psychosocial care from pre-diagnosis through all phases of the cancer experience. Navigation services and programs should be provided by culturally competent professional or non-professional persons in a variety of medical, organizational, advocacy, or community settings. The type of navigation services will depend upon the particular type, severity, and/or complexity of the identified barriers.

2. Why are cancer patient navigation programs effective?

Cancer patient navigation is an effective patient-focused program that accomplishes the following:
- Improved early cancer detection
- Increased adherence to cancer screenings and treatment
- Decreased health care costs
- Improved survival rates
- Client ease in communicating with health care professionals and assistance in accessing care/resources
- Better utilization and matching of correct medical resources for patients

3. Where can information be found about cancer patient navigation and its efficacy?

- C-Change developed an in-depth report, *Cancer Patient Navigation: Published Information,* that provides the history, definition, and efficacy of cancer patient navigation in the U.S. To access this report, visit: http://www.c-changetogether.org/pubs/pubs/CPNPaper.pdf .
- Cancer Patient Navigation, as pioneered by Harold Freeman, can be an effective tool in reaching minority populations by providing them with individualized care. This article looks at various minority populations including Native Americans, African Americans and Asian Americans. To access an article in *Cure* magazine entitled "Are Minorities Benefitting from Prevention Priority?" visit: http://www.curetoday. com/index.cfm/fuseaction/article.show/id/2/article_id/158 .
- The Harold P. Freeman Patient Navigation Institute provides information on patient navigation development and training in the Freeman patient navigation model for current and potential navigators. For more information on the Institute, visit: http://ralphlaurencenter.org/services_patient.asp?langid=1 or call (212) 987-1777. To learn more about Dr. Freeman's program and to access a breast cancer patient navigation resource kit, visit: http://www.hanys.org/quality/clinical_operational_initiatives/bcdp/resource_kits/ .
- The American Society of Clinical Oncology provides treatment plan and summary templates to improve documentation and coordination of cancer treatment and survivorship care. Search for "treatment plan and summary" at http://www.asco.org .

4. What is the cost of cancer Patient Navigation Programs?

The benefits of cancer patient navigation far outweigh the costs associated with these programs; however, the cost varies. Some programs use volunteer navigators who require oversight and supervision. Many programs use paid staff. Regional cost of living and salary variations affect startup and maintenance of programs. Some of the costs to consider when starting a Patient Navigation Program are:
- Personnel salary (i.e., social worker, nurse, lay health worker)
- Benefits
- Training
- Supervision
- Professional meetings/continuing education
- Office space and utilities
- Supplies
- Telephones including mobile phones
- Computers and networking needs
- Information technology support
- Transportation, travel/mileage reimbursement, and auto insurance protection, if home visits are included
- Marketing and outreach
- Sustainability and replacement costs from loss such as turnover of well-trained staff to other positions

5. What are potential funding sources for Cancer Patient Navigation Programs?

A 2003 National Cancer Institute survey identified more than 200 navigation programs nationally, many of which were funded by small grants from private foundations such as the Avon Foundation and Susan G. Komen for the Cure. It is important to consider all possible funding sources from local or regional community and/or corporate sources. Cancer patient navigation can be funded through sources such as:

➢ Private or public donations from community, organizational, or corporate sources
➢ Foundation grants
➢ State or federal legislation
➢ Government research grants
➢ Healthcare systems
➢ Restructuring some staff functions and employees into new positions

6. What are other potential funding sources to explore?

The following organizations and entities have supported cancer activities in the past at the national, state, or local level:

➢ **American Cancer Society,** www.cancer.org
➢ **Avon Foundation,** www.avonfoundation.org
➢ **Susan G. Komen For the Cure,** www.komen.org
➢ **Lance Armstrong Foundation,** www.livestrong.org
➢ **Centers for Medicare and Medicaid Services,** http://cms.hhs.gov Has initiated pilot navigation programs for persons over 65.
➢ **National Cancer Institute,** http://www.cancer.gov/researchandfunding
➢ **Patient Navigator Outreach and Chronic Disease Prevention Act of 2005,** http://www.govtrack.us/congress/bill.xpd?bill=h109-1812 The Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 authorized $25 million under the act to be implemented by the Health Resources and Services Administration (HRSA) through grants to provide and evaluate services.

7. What research and reports have been published to evaluate cancer patient navigation programs as a way of overcoming cancer health disparities?

➢ Harlem Hospital Cancer Control Center reports that increased access to care (through free screening) and early detection produced a survival rate of 70% over five years compared to 39% in the previous study when patient navigators were not in place. A Model Patient Navigation Program. *Oncology Issues, October, 2004.* http://www.accc-cancer.org/oncology_issues/articles/sepoc04/freeman.pdf

➢ Dr. Harold P. Freeman, a founder of the patient navigation concept, established the nation's first patient navigation program in 1990 at Harlem Hospital Center to help improve access to cancer screening and address the delays in clinical follow-up and barriers to cancer care that poor people encounter. The pilot program compared five year survival rates of breast cancer patients who were navigated and those who were not, and found an improvement in the navigated patients. In a 1995 study of 1,034 female and 105 male breast cancer patients, 87% of those with navigation assistance versus 56% of those without patient navigation completed biopsies and in less time. (Freeman, Muth, & Kerner) *Expanding access to cancer screening and clinical follow-up among the medically underserved.* Cancer Practice. 1995 Jan-Feb;3(1):19-30). To learn more about Dr. Freeman's program and to access a breast cancer patient navigation resource kit, visit http://www.hanys.org/quality/clinical_operational_initiatives/bcdp/resource_kits/ .

- *PROJECT SAFe* – The Institute for the Advancement of Social Work Research has produced an evidence-based toolkit to improve patient screening follow-up adherence through research conducted through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), 1997- 2002. Principal Investigator was Kathleen Ell, DSW.

  This project tested a systematic evidence-based case management approach to improve patient cancer screening follow-up adherence. The SAFe [Screening Adherence Follow-up] project adapted interventions for delivery in different service systems and diverse populations. Key study questions concerned the effectiveness, feasibility and utility of SAFe case management and identification of patient, provider and health systems barriers and facilitating processes to implementing SAFe in "real world" health care systems. Tested in three separate studies in multiple sites, SAFe case management improved patient adherence significantly over site baseline rates, non-enrollee rates, and control group rates, with adherence rates improving from 6 percent to 25 percent. The project developed the PROJECT SAFe Tool Kit for dissemination. CD copies of the Tool Kit may be ordered through iaswr@naswdc.org or viewed and downloaded at www.iaswresearch.org and click on Project SAFe.

- Native Sisters Program - This report describes the effectiveness of a navigator program which resulted in a significant drop in the number of women who canceled their scheduled appointments, and an increase in the number of women who called with questions or came to the clinic (Burhansstipanov L, Wound DB, et al. *Culturally relevant "Navigator" patient support. The Native sisters*. Cancer Practice. 1998; 6(3):191-4). To view the report, visit: http://www.rwjf.org/reports/grr/026400s.htm .

- American Indians and Alaskan Natives have the poorest five-year survival rates of any other racial group from all cancer sites combined. *An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*. Washington, DC: National Academy Press; 1999.) A National Action Plan for Cancer Survivorship: Native American Priorities http://natamcancer.org/NAP_Native_American_Priorities.pdf

- Screening Promise Among Black Women - In this study, black women who reported being told what was to happen next and those who remembered receiving the results of their mammogram were significantly more likely to have diagnostic resolution within three months. Kerner, J. F., et al. (2003). Realizing the promise of breast cancer screening: Clinical follow-up after abnormal screening among black women. *Preventive Medicine, 37*, 92-101. http://appliedresearch.cancer.gov/cgi-bin-pubsearch/pubsearch/index.pl?page=abstract&ID=319&project=arp

- NCI Center to Reduce Cancer Health Disparities hosts a Web page, "Patient Navigation Information." Publications, Web sites and applications on patient navigation programs, including reports on disparities from the Centers for Medicare and Medicaid and from Cancer Care Nova Scotia on Cancer Patient Navigation can be found at: http://crchd.cancer.gov/pnp/pnp-information.html .

- The Centers for Disease Control and Prevention (CDC) advocates for the development of patient navigation programs to provide the best care for cancer survivors. In *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*, the CDC notes that patient navigation is a tool that can be used to ensure that survivors fully understand their screening, treatment and prognosis. http://www.cdc.gov/cancer/survivorship/pdf/plan.pdf

- The Institute for Alternative Futures' Initiative, the Disparities Reducing Advances (DRA) Project, is created to identify the most promising advances for bringing health gains to the poor and underserved and accelerating the development and deployment of these advances to reduce health disparities. The DRA

Project has identified eight priority efforts to reduce health disparities, one of which is Consumer-Patient Navigation. To learn more, visit the DRA Project at http://www.altfutures.com/DRA/#2 .

➢ Drs. Daniel Dohan and Deborah Schrag examined the existing literature and information on patient navigation, determining that this strategy has been implemented in all phases of cancer – prevention, screening, treatment and survival – to add a flexible response to the problem. They indicate that more research is needed to determine its effects and effectiveness. http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&db=PubMed&list_uids=16010658&dopt=Abstract

➢ Oncology patient navigator nurses provide a service to the patient and the interdisciplinary team because they provide assistance to the patient in adapting to the illness and to the team by providing continuity of care. The functions and roles of the nurse navigator are presented to understand how to work with the patient and with the oncology team. http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=17078346

8. What is the status of Patient Navigation legislation?

The Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 became law on June 29, 2005. The Patient Navigator Act proposes $25 million over 5 years for demonstration programs to provide patient navigator services to improve health outcomes. To follow the CPN legislation, visit http://www.govtrack.us/congress/bill.xpd?bill=h109-1812 .

The Patient Navigator Outreach and Chronic Disease Prevention Act of 2005

This act amends the Public Health Service Act to authorize the Secretary of Health and Human Services, acting through the Administrator of the Health Resources and Services Administration (HRSA), to make grants to eligible entities for the development and operation of demonstration programs to provide patient navigator services to improve health care outcomes. It requires the Secretary to coordinate with, and ensure the participation of, the Indian Health Service, the National Cancer Institute, and the Office of Rural Health Policy.

Requires that each grantee agree to recruit, assign, train, and employ patient navigators who have direct knowledge of the communities they serve to facilitate the care of individuals, including by: (1) acting as contacts for individuals seeking prevention or early detection services for cancer or other chronic diseases; (2) facilitating the involvement of community organizations to provide better access to high-quality health care services to individuals at risk for, or who have, cancer or other chronic diseases; (3) coordinating with the relevant health insurance ombudsman programs to provide information to such individuals about health coverage; (4) notifying individuals of clinical trials; (5) helping patients overcome barriers within the health care system to ensure prompt diagnostic and treatment resolution of an abnormal finding of cancer or other chronic disease; and (6) conducting ongoing outreach to health disparity populations.

Requires the Secretary to: (1) require each grant recipient to prohibit patient navigators from accepting anything of value in return for referring an individual to a particular health care provider; and (2) prohibit the use of any grant funds to pay any fees or costs resulting from any proceeding to resolve a legal dispute. Allows the Secretary to grant awards for a period of no more than three years with a one year extension.

Requires the Secretary to: (1) direct that each application for a grant outline how the eligible entity will establish baseline measures and benchmarks that meet the Secretary's requirements to evaluate program outcomes; (2) establish uniform baseline measures in order to properly evaluate the impact of the demonstration projects; (3) give preference to those entities that demonstrate plans to utilize patient navigator services to overcome significant

barriers to improve health care outcomes within their respective communities; and (4) ensure coordination of the grant programs under this Act with existing authorized programs to facilitate access to high-quality health care services.

Requires the Secretary to study the program and report to Congress on the results to include an evaluation of program outcomes and recommendations as to whether such programs could be used to improve patient outcomes in other public health areas.

Social Work Commentary on CPN Legislation:

Author Julie S. Darnell responds to the legislation outlined above in the social work commentary on Patient Navigation: A Call to Action, *Social Work. 52(1), 81-84.* Cancer Patient Navigation programs are a promising strategy to reduce racial and ethnic disparities in health outcomes. Given that the duties of patient navigators closely align with those of a social worker, this article highlights to social workers the role they should take in planning, leading and executing Cancer Patient Navigation programs. To view, visit: http://findarticles.com/p/articles/mi_hb6467/is_1_52/ai_n29335756/ .

Patient Navigator Tools

When individuals are diagnosed with cancer, they are often overwhelmed. They know life is going to be dramatically impacted and changed forever. They are often confused, overwhelmed and unsure.

As with many life-changing events, cancer patients must go through many phases. They sometimes experience denial (this can't be happening!), sorrow (why is this happening to me?), recognition (this has happened, now what?), and acceptance (alright, I am ready to fight this!).

Throughout these phases and particularly when entering the acceptance phase, patients need information, support and services.

Cancer rarely involves a one time visit to a doctor's office. A cancer diagnosis often sets patients on a path involving multiple health services. Surgery, chemotherapy, radiation therapy and/or a combination of all three are often a part of their journey. Patients may see a primary care physician, be referred to an oncologist, see a radiation therapist and be cared for by nurses and technicians in-between. They may receive treatment in a doctor's office, in a hospital setting or in a cancer center. These systems of care can provide the life-saving measures needed for cancer patients, but they can also be frustrating and overwhelming.

The following sample documents can be used to assist organizations with the implementation of Patient Navigation Programs.

Patient Navigator
Position Description

Position Description:
Cancer Patient Navigator

Reports to:
[supervisor/organization/program]

Summary of responsibilities:
The Navigator position is within the [program] located at [organization] in [city]. [Program] is a network of hospitals, physician group practices, and not-for-profits united to enhance cancer care at the community level in [area served]. Using a combination of communication strategies, the successful candidate will assist cancer patients in [area served] to anticipate, identify, and overcome barriers within the health care system, including understanding their diagnosis, coordinating their treatment plans, seeking assistance for appropriate social services, and communicating with their treatment team, family, and significant others. The successful candidate will document interactions and outcomes. The Navigator will also work closely with appropriate staff at partner sites and other hospitals and clinics to build trust and a shared commitment to serving cancer patients at the community level. Travel is required.

Minimum Qualifications:
Bachelor of Science in Nursing or Masters in Social Work or other relevant education. Three years experience in a clinical setting assisting patients locate resources locally, regionally, and nationally. Knowledge of environment and systems in which patients receive care. Excellent written and verbal communication skills. Detail-oriented. Good computer skills.

Preferred Qualifications:
Masters degree in nursing. Microsoft Office proficient. Management experience. Grant funding experience. Bilingual.

Duties:
Quickly acquires and maintains strong knowledge of local, state, and national cancer-related resources and services to assist cancer patients and their families to manage their disease and its impact on daily living.

Quickly develops and maintains strong communication within the [organization/program].

Establishes and maintains regular communication with a network of practitioners with like responsibilities throughout the region regarding sharing of knowledge of cancer resources.

Assists the Program Director and Medical Director in establishing and maintaining quality reporting responsive to the needs of a range of funders.

Patient Navigation Intake Form and Tracking Tool

(Complete this form with the patient at the initial visit.)

Are you the: ☐ Patient   ☐ Loved One   ☐ Caregiver

Name: _____

Address: _____

Telephone number(s): (_____)_____

Can messages be left at this phone number?   ☐ Yes   ☐ No

Emergency contact person: _____

Telephone number: (_____)_____

Primary caregiver (if different): _____

Telephone number: (_____)_____

1. Why were you referred to the patient navigation program? _____

_____

_____

2. How were you referred to the patient navigation program?

☐ Physician   Name: _____

☐ Hospital   Name: _____

☐ Clinic   Name of clinic: _____

☐ Screening center   Name of center: _____

☐ Nurse   Name and department: _____

☐ Social worker   Name: _____

☐ Other   Please explain: _____

3. What concerns might keep you from getting to all of your appointments (for example, child care or transportation needs, job responsibilities, or finances)? **[Note to Navigator: Refer to list of possible barriers to help patient identify concerns.]**

_____

_____

_____

4. How do you feel patient navigation can best help you? _____

_____

_____

5. Do you have health insurance? ☐ Yes ☐ No

If **yes**, is it: ☐ Private/Commercial ☐ Medicare ☐ Medicaid

☐ Other: _____

If **no**, are you currently working on getting health insurance (for example, Medicaid, COBRA, etc.)?

☐ Yes ☐ No

Please explain: _____

_____

_____

6. Are you a citizen of the United States? ☐ Yes ☐ No

If no, please provide information about your residency: _____

_____

_____

LEARNING PREFERENCES

7a. What is your native language? _____

b. What other languages do you speak? _____

What other languages do you write? _____

What other languages do you read? _____

c. In what language(s) do you feel the most comfortable when you are hearing new information?_____

8. Which of the following methods is most helpful when learning about your health (when they are in your preferred language)? *(Check all that apply.)*

    ☐ Reading   ☐ Watching a video

    ☐ Listening (person-person)   ☐ Personal demonstration

SUPPORT SYSTEM

9. Who do you have available to help you at this time with issues such as transportation, child care, support, etc.? _____

_____

10. Who is available to help you at home? _____

_____

11. How have your family or other loved ones responded when you have needed help?

_____

_____

POTENTIAL PROBLEMS/BARRIERS TO CARE

This list is to be used to help you to identify patient concerns at the initial visit and at each follow-up visit. It will help you develop a plan of action, including referrals to appropriate departments.

Health Insurance/Financial Concerns

- ☐ Inadequate or lack of insurance coverage
- ☐ Pre-certification problems
- ☐ Difficulty paying bills
- ☐ Need for financial assistance from Medicaid/Medicare
- ☐ Confusing financial paperwork
- ☐ Need for prescription assistance
- ☐ Need for medical equipment or supplies (wheelchairs, dressings)
- ☐ Citizenship problems/undocumented status
- ☐ Other: _____

Transportation To and From Treatment

- ☐ Public transportation needed
- ☐ Private transportation needed
- ☐ Ambulette (independent ambulance transportation) services required
- ☐ Other: _____

Physical Needs

- ☐ Child/elder care
- ☐ Housing/housing problems
- ☐ Food, clothing, other physical needs
- ☐ Prostheses, wigs, etc.
- ☐ Vocational support (job skills, employment skills)
- ☐ Extended care needs: home care, hospice, long-term care
- ☐ Other: _____

Communication/Cultural Needs

- ☐ Primary language other than English
- ☐ Inability to read/write
- ☐ Poor health literacy
- ☐ Cultural barriers (i.e., effect on lifestyle choices)
- ☐ Other: _____

Disease Management

- ☐ Treatment compliance issues (missed appointments, unwillingness to take medicine)
- ☐ Needs help with obtaining a second opinion (if desired by patient)
- ☐ Mental health services needed
- ☐ Does not understand treatment plan and/or procedures
- ☐ Needs to talk to provider (physician, nurse, therapist, etc.)
- ☐ Wants more information about: _____
- ☐ Other: _____

[Note to Navigator: Add to this list as you encounter other barriers to care. Below is a list of support services. You may need to suggest that the patient ask his or her health care provider about a referral.]

Supportive Services for Referrals

- ☐ Social workers
- ☐ Clergy
- ☐ Nutritionists
- ☐ Genetic counselors
- ☐ Financial counselors
- ☐ Physical, occupational, and speech therapists
- ☐ Psychologists
- ☐ Board-certified psychiatrists specializing in hospice/palliative medicine

<u>Tracking Tool</u>

Refer to POTENTIAL PROBLEMS/BARRIERS TO CARE to explore patient concerns.
Record the results of each intervention or visit with the patient.

Patient name and identification: _____

Date: _____

Reason for visit: _____

Barrier/concern identified: _____

Action to be taken: _____

_____

_____

Desired result: _____

Resolution and date: _____

Additional comments: _____

_____

_____

Patient name and identification: _____

Date: _____

Reason for visit: _____

Barrier/concern identified: _____

Action to be taken: _____

_____

_____

Desired result: _____

Resolution and date: _____

Additional comments: _____

_____

_____

<ins>YOU ARE NOT ALONE</ins>

The [Facility Name] Patient Navigator can help you by:

- ❖ guiding you through the health care system;

- ❖ advocating on your behalf to enhance your communication with health care staff and providers;

- ❖ working with you to find the resources and support you need;

- ❖ helping you find appropriate sources to pay for your health care needs;

- ❖ helping you arrange screening services;

- ❖ streamlining your health care appointments; and

- ❖ helping you arrange for appropriate services so you can keep your health care appointments.

For more information contact **[Patient Navigator Name]**, the Patient Navigator at **[Facility]** at **[Contact Information]**.

SAMPLE

[Facility Logo]

Patient Navigator Program
<u>Patient Satisfaction Survey</u>

[FACILITY NAME]
[FACILITY ADDRESS]

Please take a moment to share your comments with us. Your comments will be used to evaluate and improve the Patient Navigator program. Please mark only one answer for each question.

Please answer the following by checking the appropriate choices:

	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Doesn't Apply
1. The Patient Navigator was courteous.	☐	☐	☐	☐	☐
2. The Patient Navigator was sensitive.	☐	☐	☐	☐	☐
3. The Patient Navigator was respectful.	☐	☐	☐	☐	☐
4. The Patient Navigator was friendly.	☐	☐	☐	☐	☐
5. The Patient Navigator was thorough.	☐	☐	☐	☐	☐
6. I valued working with the Navigator.	☐	☐	☐	☐	☐
7. The education materials received were helpful.	☐	☐	☐	☐	☐
8. The support services referrals received were helpful.	☐	☐	☐	☐	☐
9. The financial information received was helpful.	☐	☐	☐	☐	☐
10. I would recommend this service to others.	☐	☐	☐	☐	☐

What suggestions do you have for improving this service?

_____

_____

_____

_____

_____

****

If you would like to discuss your experience, please include your name and contact information:

Name: _____

Telephone (or other contact information): _____

Best time to contact you: _____

Thank you for your input.

SAMPLE

<u>Press Release</u>

FOR IMMEDIATE RELEASE   **FOR MORE INFORMATION**
DATE   **CONTACT NAME**
        CONTACT NUMBER

[FACILITY NAME] ANNOUNCES THE NEW PATIENT NAVIGATOR PROGRAM

[CITY], KS, [FACILITY NAME] is pleased to announce the expansion of its oncology support services with the addition of a Patient Navigator Program.

Recognizing that the complexity of the health care system often leaves patients feeling confused, lost, or alienated, the Patient Navigator helps patients by guiding them through the various services involved and connecting them with appropriate resources and support.

The Program's goals include improving patient satisfaction and enhancing access to cancer prevention, early detection, and treatment.

[QUOTE FROM FACILITY CHIEF EXECUTIVE]

Cancer Treatment Plan and Summary

The American Society of Clinical Oncology's "chemotherapy treatment plan and summary templates were developed to help improve documentation and coordination of cancer treatment and survivorship care. They are intended to facilitate provider-to-provider and provider-to-patient communication - the templates may be distributed to patients or providers as records of the care planned and received. Importantly, the treatment plan and summary are not intended to replace detailed chart documentation, including complete patient histories or chemotherapy flow sheets." The following is a sample treatment record which may be used for any cancer; other cancer-specific records may be found by searching for "treatment plan and summary" at http://www.asco.org .

[Insert Practice Name/Info Here]
The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.

Patient name:	**Patient ID:**
Medical oncology provider name:	**PCP:**
Patient DOB: (___/___/___) **Age:**	**Patient phone**:
Support contact name:	
Support contact relationship:	**Support contact phone**:

Symptoms/signs:

Family history/predisposing conditions:

Major co-morbid conditions:

Tobacco use: □ No □ Yes, past □ Yes, current **(If current, cessation counseling provided?**: □ Yes □ No**)**

Cancer type/location: **Diagnosis date:** (___/___/____)

Is this a new cancer diagnosis or recurrence?: □ New □ Recurrence (date: ___/___/____)

Surgery: □ None □ Diagnosis only □ Palliative resection □ Curative resection

Surgical procedure/location/findings:

Tumor type/histology/grade:

Study	Date	Findings

T stage: □ T1 □ T2 □ T3 □ T4 □ Not applicable | **N stage:** □ N0 □ N1 □ N2 □ N3 □ Not applicable

M stage: □ M0 □ M1 □ Not applicable | **Tumor markers:**

Stage: □ I □ II □ III □ IV □ Recurrence | Alternative staging system: _____

Location(s) of metastasis or recurrence (if applicable):

TREATMENT SUMMARY

White sections to be completed prior to chemotherapy administration, shaded sections following chemotherapy

Height: ___ in/cm | **Pre-treatment weight:** ___ lb/kg | **Post-treatment weight:** ___ lb/kg

Pre-treatment BSA: | **Treatment on clinical trial:** □ Yes □ No

Name of chemotherapy regimen:

Chemotherapy start date: (/ /) | **Chemotherapy end date:** (/ /)

Chemotherapy intent: □ Curative, adjuvant or neoadjuvant □ Disease or symptom control

ECOG performance status at start of treatment: □ 0 □ 1 □ 2 □ 3 □ 4 | **ECOG performance status at end of treatment:** □ 0 □ 1 □ 2 □ 3 □ 4

Chemotherapy Drug Name	Route	Dose mg/m^2	Schedule	Dose reduction	# cycles administered
				□ Yes _____% □ No	
				□ Yes _____% □ No	
				□ Yes _____% □ No	
				□ Yes _____% □ No	
				□ Yes _____% □ No	
				□ Yes _____% □ No	

Major side effects of this regimen: □ Hair loss □ Nausea/Vomiting □ Neuropathy □ Low blood count □ Fatigue □ Menopause symptoms □ Cardiac □ Other _____

[Insert Practice Name/Info Here]

The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.

			TREATMENT SUMMARY (CONTINUED)
Non-chemotheraputic Agents	**Route**	**Purpose/Goal**	**Comments**

Reason for stopping treatment: □ Completion
□ Toxicity □ Progression □ Other: _____

Response to treatment: □ Complete   □ Partial
□ No response   □ Progression   □ Not measurable

Treatment-related hospitalization required:
□ Yes □ No

Serious toxicities during treatment (list all):

Ongoing toxicity at completion of treatment:
□ Yes (enter type(s) and grade(s) _____)
□ No

Drug name	Comments	Date started (or to start)
		(___ / ___ / ___)
		(___ / ___ / ___)
		(___ / ___ / ___)

Radiation therapy: □ Not planned
                                  □ Planned
                                  □ Administered   Region treated: _____   Radiation dose: _____
                                                          Date initiated: (___ / ___ / ___)   Date completed: (___ / ___ / ___)

	SURVIVORSHIP CARE PROVIDER CONTACTS
Provider: Name: Contact Info:	**Provider:** Name: Contact Info:
Provider: Name: Contact Info:	**Provider:** Name: Contact Info:
Provider: Name: Contact Info:	**Provider:** Name: Contact Info:
Provider: Name: Contact Info:	**Provider:** Name: Contact Info:

[Insert Practice Name/Info Here]

The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.

Follow up care	When/How Often?	Coordinating Provider
Medical oncology visits		
Lab tests		
Imaging		

Potential late effects of treatment(s):

Call your doctor if you have any of these signs and symptoms:

Needs or concerns:
□ Prevention and wellness: _____

□ Genetic risk: _____

□ Emotional or mental health: _____

□ Personal relationships: _____

□ Fertility: _____

□ Financial advice or assistance: _____

□ Other: _____

Referrals provided:
□ Dietician
□ Smoking cessation counselor
□ Physical therapist or exercise specialist
□ Genetic counselor
□ Psychiatrist
□ Psychologist
□ Social worker
□ Fertility specialist or endocrinologist
□ Other: _____

Comments