

## Mission

*To promote excellence in oncology patient care by fostering collaborative relationships and professional development among oncology nurse navigators and all healthcare disciplines locally, regionally, and nationally*

## Vision

*To be the national leader in establishing standards that define the oncology nurse navigator role by advocating for the oncology nurse navigator within the community and professional arenas*

# Quarterly Newsletter

## National Coalition of Oncology Nurse Navigators

# January 2012



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DEDICATED TO THE SUPPORT OF THE ONCOLOGY NURSE NAVIGATOR

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## NCONN's 4<sup>th</sup> Annual Conference

Today, NCONN is delighted to be able to announce that we are heading back to Nashville October 4-6<sup>th</sup>, 2012.

In the spring of 2010, NCONN had to move our 2<sup>nd</sup> annual conference scheduled for October from Nashville, TN to Branson, MO due to the epic 50-year flood that devastated Nashville, the Middle Tennessee, and Cumberland River Valley. The Cumberland River topped out at just less than 52 feet. Hundreds of people were rescued and thousands of families, and businesses were damaged including the Grand Old Opry and Gaylord Opryland Hotel.

When 2010 and 2011 conference attendees were asked what city would they like to see the next NCONN conference held Nashville placed one and two respectively. Over the past three years, NCONN has learned much from our conference evaluations and we are dedicated to taking the comments/suggestions and ensuring that we LISTEN.

Top programs requested for the next NCONN conference:

- Disease specific navigation program development
- Breakout sessions to discuss individual navigation programs

- Developing a survivorship program in a community setting
- Data collection systems
- Implementing treatment summary plans
- Grant writing
- ACoS Standards

The good news is each of these topics will be presented at the NCONN conference in breakout sessions. In addition, each attendee will have an opportunity to attend each breakout session and won't have to choose one over another. Special note those of you who are Breast Navigators and need breast specific CEU's for your certification will also be able to satisfy most of these at one conference.

Please join us in Nashville, registration is opening this week and a tentative agenda will be posted on the NCONN website in the next several weeks.

Healthy Wishes, Sharon

Gaylord Hotel Direct Line for Reservations:

1-615-883-2211

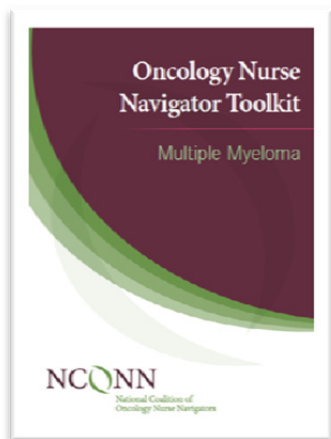
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## Oncology Nurse Navigator Toolkit: Multiple Myeloma



In 2011 NCONN members worked on several projects, one of which was the Oncology Nurse Navigator Toolkit for Multiple Myeloma.

The goal of NCONN is to provide oncology nurse navigators with the resources, support, guidance and tools needed to effectively perform their role. One way that NCONN is able to do this is by working together to improve processes and develop standards of care in navigation. NCONN is pleased to announce the first completed ONN toolkit.

Active paid members may access the ONN toolkit for Multiple Myeloma by visiting the website [www.nconn.org](http://www.nconn.org) logging in and clicking on the Discussion Forum tab. Currently the toolkit is view only. Once funding is available, we hope to provide each member with a printed copy. To purchase a printed copy of the ONN Multiple Myeloma Toolkit you may contact Lou Ann Mercier at [lmecier@nconn.org](mailto:lmecier@nconn.org). Price for one copy is \$12 (this includes printing and postage).

**Are you interested in working on disease specific ONN toolkits? Please take the online survey at:**

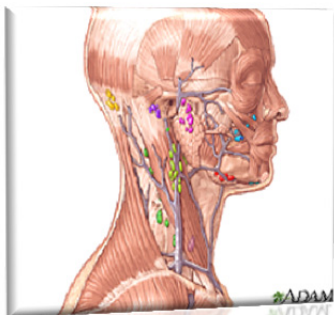
<http://www.zoomerang.com/Survey/WEB22EP5M23YJL>

## Navigator Best Practice

When navigating head and neck cancer patient's challenges arise that require additional resources and raise new concerns. Below is one navigator's process improvement report. Do you have a ONN best practice that you would like to share? Email to [newsletter@nconn.org](mailto:newsletter@nconn.org)

### Process Improvement for Head and Neck Cancer Patients 2011

*NCONN member: Diane McElwain, RN, OCN, M,Ed  
Reported at Cancer Committee 11/16/11*



### Head and Neck Cancer Support Group Expressed needs:

- Feeding tube issues
- Post treatment side effects
- Rehabilitation concerns (lymphedema, swallowing issues and Range of motion problems)
- Support Issues

### Oncology Staff Concerns:

- Feeding tube process issues and reimbursement
- Dental Center processes
- Rehab Medicine scheduling

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The Head and Neck Cancer Support Team consists of surgeons, medical and radiation oncologists, Radiation Therapy and medical oncology nurses, a nurse navigator, two oncology dietitians and rehabilitation therapy staff.

### Tasks Completed:

#### Feeding Tube Issues:

1) The support team (Radiation Therapy, nurse navigator and oncology dietitians) worked with Interventional Radiology Staff to

streamline care and improve handoffs after gastric tube insertions.

2) The Radiation Therapy nurse manager instituted a procedure for post procedure teaching for these patients.

3) The Radiation Nurse Manager is working on a patient satisfaction study regarding educational issues around the gastric tube use.

4) The Nurse Navigator reported the original PEG Study on 5/4/11 and completed a repeat study regarding Interventional Radiology procedure notes and adequate post procedure charting on the Radiation Therapy charts on 11/8/11. For 13 cases of gastric tube insertions since May, procedure notes were found on all charts as well as post procedure notes by Radiation Therapy staff on all charts. This is an improvement since the original study.

5) The oncology dietitians worked out a system of referral for tube feeding patients with Wellspan Infusion since reimbursement for these products has changed.

### Post Treatment Side Effect Issues:

The Nurse Navigator will begin a phone call program between the already scheduled post treatment visits.

The oncology dietitians already have a call system for these patients.

### Rehabilitation Issues:

1) Patients have been expressing needs about swelling, difficulty swallowing and neck Range of Motion problems. The Rehabilitation Medicine program already has a program in place for breast cancer patients and we have expanded this to head and neck cancer patients. Patients will be sent for a routine appointment to a physical therapist

**More than 52,000 men and women in this country were expected to be diagnosed with head and neck cancers in 2011**

for an evaluation post treatment for an assessment and treatment visit. Speech Therapy consults were already in place and are being refined.

2) Lymphedema and Range of Motion problems will be assessed earlier. The Rehabilitation Services Oncology Services brochure will be distributed to these patients on the last day of Radiation Therapy treatment.

3) Rehabilitation Services has expanded to 3 locations and attempts are being made for oncology patients to be centered in Apple Hill site.

4) Laura Schmitt, PT and Dianne Hollinger, speech therapist, have presented programs to the Head and Neck Cancer Support Group and solicited referrals. This is a way for patients to ask for services.

4) A letter with the improved services for these patients has gone out to the clinicians.

#### Dental Center Referrals:

There was perception from Dental Center staff that customer service could be improved. We have met with their staff and appointments have been placed into their schedule for better patient access and key staff will be involved with communication.

#### Support Issues:

The support team continues to actively solicit from patients and families and invites all new patients to the group.

**Tobacco use, alcohol use, and human papillomavirus infection are important risk factors for head and neck cancers.**

## The NCCCP Navigation Matrix – a tool you can use to build a stronger program

Karen Masino, MS, CNP, ACNP-BC, AOCNP, RN, RD, LDN [kmasino@ingalls.org](mailto:kmasino@ingalls.org)

The National Cancer Institute (NCI) established the Community Cancer Centers Program (NCCCP) in 2007 to develop a network of hospital cancer centers that would be able to explore the best methods to support research initiatives, improve access to clinical trials for patients and improve the quality of care across the cancer continuum. Goals of the NCCCP are to enhance access to care, particularly for patients in underserved communities, improve the quality of care and expand research.

Toward meeting these program goals, the NCCCP has developed a number of useful tools that are available on the NCI website.

One of the tools that the NCCCP has developed is a navigation matrix which was released on July 14, 2011 to provide a guideline for community based hospitals to improve the quality of navigation services and to develop stronger programs.

The matrix has identified sixteen key categories which are recommended for inclusion into a navigation program. These key areas are then plotted against a five level grid that provides a description of the depth of services in each of these key areas by level. Level I provides the most basic of services, while level five defines services that meet benchmark status.

As an example, one of the key categories is "marketing of the navigation program". Each level includes services at the previous level, plus the addition of services defined in succeeding levels

Level I describes marketing as **occurs by word of mouth**

Level II describes marketing as **plus some basic written material (i.e. pamphlet)**

Level III describes marketing as **navigator participation at health fairs, cancer screening events as a means of marketing cancer program**

Level IV describes marketing as **plus effort made to promote navigation in some media form**

Level V describes marketing as **plus multiple sources of media used to support navigation.**

It should be noted that each level builds on the previous level to increase the effectiveness of the key category in building a stronger navigation program which is in this case "marketing".

The intent of the matrix is to provide cancer programs a basis for self-assessment and the ability to set concrete goals to achieve a stronger program.

The NCCCP has also developed a number of other useful tools for cancer program development. The navigation matrix as well as additional NCCCP resources can be accessed at:

<http://ncccp.cancer.gov/about/reports-and-tools.htm> 1

Some of the other resources available include a breast screening tracking tool, a template for community outreach, a multidisciplinary assessment tool, and a psychosocial and palliative care matrix to name just some of the resources.

Cancer programs need to be designed according to the populations that they serve. These resources can be very helpful in providing guidance on methods to increase the quality of the program. All navigators should access the NCCCP website to take advantage of the resources that are available.

1 NCI community cancer centers program, progress reports and tools. Accessed November 22, 2011.



**4th Annual  
NCONN Conference  
Nashville, TN  
October 4-6, 2012**





## GSI Offers Free Materials for Patients with Gastrointestinal Stromal Tumor (GIST)

[gsi@gistsupport.org](mailto:gsi@gistsupport.org)

GIST Support International (GSI) is an all-volunteer nonprofit organization serving patients with gastrointestinal stromal tumor (GIST). Although GIST is the most common sarcoma, it is still a rare cancer, and most people have never heard of it before being diagnosed. Patients typically feel overwhelmed when learning that they have a cancer for which there are no local support groups and no local network of survivors to help them. Our mission in GSI is to provide education and support to those affected by GIST worldwide.

**Online and telephone interactive support:** GSI offers a cyber-community of patients with GIST who help each other ease the anxiety and isolation of contracting a rare disease. GSI operates two active listservs for patients, family members, and anyone interested in GIST: the larger one with over

1500 members is for all those affected by GIST, and the smaller one is for pediatric and adult patients with wildtype GIST (having no mutations in the genes for KIT or PDGFRA). GSI's listservs are true online communities where patients ask questions, share tips and experiences, and receive support in facing this rare sarcoma. We also have a phone helpline and provide phone pals.

**Information:** Our website and wiki provide comprehensive information about GIST and current treatment options from first-line therapies to clinical trials. Patients can watch videos of presentations made by experts at our annual GIST Summit meeting and can read question-and-answer discussions by top oncologists, radiologists, nutrition experts, and other professionals.



**Inspiration:** For personal psychological encouragement our website includes individual stories, essays, and videos of patients sharing how they are living successfully with GIST. Survivorship with GIST differs from cancers that have a defined treatment regimen and an "after-treatment" phase. Recurrent or metastatic GIST is treated with oral tyrosine kinase inhibitors that are taken indefinitely, so the patient never finishes treatment.

Patients may measure their lives in segments between quarterly scans. GSI helps patients and caregivers deal with the uncertainties and the anxiety that tumors may become drug-resistant.

- **Materials:** We encourage navigators to request these free materials to assist in educating and counseling GIST patients: Brochures "*Understanding GIST*" explaining GIST basics, treatments, and questions to ask your doctor. These are suitable for a literature rack.
- **Booklets "*Understanding Your GIST Pathology Report*"** explaining where GIST may develop, its molecular causes, how it is diagnosed, and how the tumor characteristics described in the pathology report determine the patient's prognosis, the probability of recurrence, and the types of follow-up and treatment needed after successful surgery. This comprehensive booklet authored by expert pathologists Jason Hornick and Alexander Lazar is a valuable tool for patient counseling and a permanent reference for patients to read at home. It includes full-color illustrations, answers to common questions, and a glossary.

**To request free materials** simply e-mail [gsi@gistsupport.org](mailto:gsi@gistsupport.org) and tell us how many copies you need and your name and mailing address. We will gladly supply your clinic!

## Oncology Nurse Navigators and Community Health Workers: Building Unique Relationships for Cancer Care

### Part I of II

Amy Sebastian-Deutsch, DNP, RN, CNS, AOCNS, APN, System Cancer Services Memorial Hermann Hospital System



With the current economic strife we are facing in healthcare today, finding ways to deliver quality survivorship care for cancer patients has become a tremendous challenge for oncology nurse navigators

(ONN). It will become even more overwhelming with the estimated 20 million cancer survivors expected by the year 2020. Being willing to forge new relationships will help meet the expected increase in demand for cancer care.

### An Idea Forms

In October 2010, the author attended the 6th Annual Breast Health Summit of Texas where she had the opportunity to participate in a roundtable session pertaining to the topic of Community Health Workers (CHW). In simplest terms, CHWs are members of a community, who have been chosen by various entities to provide basic healthcare within the community in which they reside.

The roundtable session was presented by faculty and CHW students from the Houston Community College (HCC) Coleman College for Health Sciences. Concepts related to disparate populations frequently having mistrust of hospital "white coat" workers, and perceptions that hospital professionals often "talk down" to impoverished clientele were discussed. Since CHWs frequently reside among the populations they serve, they are more often trusted. This can afford CHWs the opportunity to help decrease feelings of mistrust experienced by the populations they work with. Following the session, the author became excited by all the possibilities that could result from establishing a collaborative bond between the CHW and the ONN; not the least of which could be referral of community residents to a known entity---the ONN.

Having spent the last 32 years working primarily in hospital and home care settings in Pennsylvania, Louisiana, Nevada and Texas, the author had never heard of the CHW role. She was even more astonished to learn there was a CHW program in Houston which offered formalized college credit to CHW students and included a practicum option; the first college program in the state. In fact, the current CHW cohort was even partially sponsored by the Susan G. Komen for the Cure Houston. Therefore, the curriculum was designed to provide some emphasis regarding the breast cancer patient population and the importance of breast health awareness.

The idea of a collaborative relationship between the ONN and the CHW began to formalize (in this case, through a preceptor/ student practicum), but first, the author had to learn more about the CHW role and also share the ONN role with college faculty (who were not familiar with the ONN position).

Researching the CHW Role

To start the process, she met with the program faculty lead instructor for the HCC CHW program, and learned the following:

- CHWs have been recognized in both the United States and worldwide for the past 50 years.
- In the US, they were first documented about in the 1950s as an entity that worked with farm workers in Florida.
- In the 1960s, the New York City Health Department included CHWs in helping them with a tuberculosis program
- In the late 1960s, CHW programs were developed to help with the Native American populations.
- In 1978, The World Health Organization recognized the CHWs as becoming a “symbolic milestone” that would become part of the healthcare workforce.
- The CHW officially arrived in Texas in 1989.

During the meeting, the author provided a brief history of the patient navigator role as developed by Dr. Harold Freeman, more than 20 years ago. She then presented the hospital system’s job definition of the ONN, required qualifications (which included being an oncology certified nurse), and their role delineation/description. She further explained that there were nine (9) ONNs located at 7 out of the system’s 11 acute care facilities; the ones with cancer programs accredited by the American College of Surgeons Commission on Cancer.

But this was just the beginning. The information learned in the meeting with HCC faculty provided the impetus for a further review of the literature. In fact, the author learned CHWs had been utilized to help get necessary healthcare to rural populations all around the world. It also seemed the CHW role was quite similar to the initial navigator role started by Dr. Freeman out of Harlem Hospital; both positions dedicated to helping impoverished populations get the care they need. International examples of the use of CHWs are depicted in Table 1.

More recently, the U.S. Department of Labor created a job line (DOL-21-1094) for the CHW. It defines the role to include: “assisting individuals and communities to adopt healthy behaviors, and conducting outreach for medical personnel or health organizations to implement programs in the community that promote, maintain, and improve individual and community health. They also may provide information on available resources, provide social support and informal counseling, advocate for individuals and community health needs, and provide services such as first aid and blood pressure screening. Finally, they might collect data to help identify community health needs.”

The Texas Department of State Health Services (DSHS) defines the CHW as a person who may or may not receive compensation but whose duties include the following:

- provide cultural mediation between their communities and health and human service systems;
- provide informal counseling and social support;
- provide culturally and linguistically appropriate health education;
- advocate for individual & community needs;
- assure people get the services they need;
- build individual and community capacity;
- or provide referral and follow-up services.

Using the eight (8) core competencies developed by DSHS – advocacy, capacity building, communication, interpersonal relations, knowledge, organization, service coordination, and teaching – the CHW can work within a community and collaborate with the ONN to assist cancer survivors or possible future cancer patients to navigate the health care system throughout the care continuum.

Additional articles were then reviewed, in order to gain further knowledge about CHW interventions which resulted in successful outcomes. Examples of CHW associated successes include:

- Kenya S, et al. conducted a review of the literature between May 2010 to November 2010 to identify studies carried out in the USA that utilized CHWs to improve highly active antiretroviral therapy (HAART) adherence, measured HIV viral loads and CD4 cell counts to assess intervention effects. Sixteen studies that met the inclusion criteria were reviewed. It was found that with
- In the Seattle-King County Area (2005), three CHWs assisted with an asthmatic management program. CHWs conducted education on management of medications and reduction of in-home asthmatic triggers (after conducting home environmental assessments). They provided on-going coaching, as well.

Country	Year(s)	Name	Comments
China	1940s	Barefoot doctors	Initiated by Chairman Mao Tse Tung due a lack of medical care for the rural population
Brazil	1990s	Community Health Agents	Family Health Program; to reduce infant mortality rates
Iran	1984 – ongoing	behvarz	Reduce infant mortality rates, monitor child growth, family planning in the underserved population.
India	2010 - ongoing	Community Health Worker	To increase mental health service utilization
Tanzania	2004 - ongoing	Village Health Workers	Community based safe motherhood approach – assisted pregnant women with safe birth planning

Table 1. Community Health Workers and their Delivery of Healthcare around the World.

Services were provided to registered clients in English, Spanish and Vietnamese. The impact of the CHWs was measured using randomized controlled trials. Study results included the following: The number of days with asthma symptoms were reduced by 4.7 days, the quality of life for caregivers improved by 1.6 on the Pediatric Asthma Caregiver Quality of Life Scale (ranging from 1 to 7, with higher scores indicating better quality of life), children went to the emergency room and hospital less often, and children who needed urgent medical attention declined by 64%. From a fiscal perspective, health care costs for hospital stays, emergency department visits and unexpected clinic appointments, decreased by an estimated \$201-\$334 per child (across 2 months).

- Hunter et al (2005) conducted a randomized controlled intervention using *promotoras* on the Texas Mexico border to increase the use of preventive screening exams among women residing there. The control group received postcard reminders of scheduled screening appointments for pap tests, labs and blood pressure checks. The intervention group also received reminder visits by the *promotoras*. The group that received the visits from the *promotoras* had a 35% increase in actual visits to get the free screenings.

The author went on to query other health care providers within her hospital system to see if they were cognizant of this healthcare position. Of all individuals queried across 7 campuses, only one individual had heard of the CHW and that nurse had "worked with them down in the valley near Brownsville, Texas." With self-education completed, the author now felt more prepared to "pitch" the proposed collaborative effort.

## PART II in next newsletter

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## What is a list-serv?

When e-mail is addressed to a LISTSERV mailing list, it is automatically broadcast to everyone on the list. The result is similar to a newsgroup or forum, except that the messages are transmitted as e-mail and are therefore available only to individuals on the list. To join list-serv, contact [Imercier@nconn.org](mailto:Imercier@nconn.org)

## TOP 10

- #1 Navigator Software
- #2 Survivorship Celebration
- #3 Navigators Disclose Biopsy Results
- #4 Distress Scales/Assessment and surveys
- #5 Using computer tables with patients
- #6 Navigator Salaries
- #7 Navigator Documentation
- #8 Oral Chemo
- #9 Pink Glove Dance
- #10 Consent forms





## Fall 2011 Survey Question Results

Q1. Which of these Competency areas ranks number one in developing standards of practice for the Oncology Nurse Navigator?	Respondents
Competence Area 1: Professional, Legal and Ethical Nursing Practice	30%
Competence Area 2: Health Promotion and Health Education	21%
Competence Area 3: Management and Leadership	12%
Competence Area 4: Advocacy	23%
Competence Area 5: Personal Effectiveness and Professional Development	14%

Q2. Do you have a Twitter account?	Respondents
Yes	8%
No	92%

Q2. The facility I work in has a Survivorship Program?	Respondents
Yes	33%
No	67%

NCONN is a registered  
non-profit 501(c)(3) organization

Q4. I wish NCONN would...
Be more active in the Atlanta area
Get the word out that nurse navigators do exist and their role and their educational background.
Have a certification program.
Be more visible
Partner with a professional physicians group to increase general physician awareness of nurse navigation
Let all members have access to the tool boxes. Identify mentors for specific disease site programs.
have <u>listserves</u> that were site specific
Work on a way so the list serve questions don't come back with an out of office reply.
Develop ONN certification
Promote site specific navigation for cancers other than breast cancer. Discuss nursing scope of practice related to navigation, it seems like many navigators don't respect the professional boundaries from the board of nursing.
Distribute the Lung/Thoracic tool kit for navigation when completed.
Provide more information to assist navigators who are new to the role and whose employer are also new to the role.
Be more visible in communication of its work and promotion of the role of nurse navigation.
Hold online certifications in various navigation areas.

Special thanks to our 2011 3<sup>rd</sup> Annual Conference sponsors:



Many thanks to our partner

## Winter 2012 Survey

To take the survey, go to [www.nconn.org](http://www.nconn.org) or  
<http://www.zoomerang.com/Survey/WEB22EP5M23YJL>

### Questions

1. I would like to see more Oncology Nurse Navigator (ONN) Disease Specific Toolkits
2. I would like to work on an ONN toolkit committee
3. This is the next ONN Toolkit I would like to see available for NCONN members
4. I will be attending the 4th NCONN conference in Nashville
5. I want to make a suggestion for the 4th Annual NCONN Conference in Nashville, Oct 4-6, 2012

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Contact us:

(800)581-0175 P.O. Box 1688, Rockville, MD 20849-1688

[newsletter@nconn.org](mailto:newsletter@nconn.org)

[info@nconn.org](mailto:info@nconn.org)

[executives@nconn.org](mailto:executives@nconn.org)