A Patient Navigator Manual for Latino Audiences: The *Redes En Acción* Experience

*Redes En Acción*
The National Latino Cancer Research Network

INSTITUTE FOR HEALTH PROMOTION RESEARCH

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About the Manual

A Patient Navigation Manual for Latino Audiences: The Redes En Acción Experience outlines the necessary steps and provides tools to incorporate patient navigation for Hispanics/Latinos at an organization. The manual was created by Redes En Acción: The National Latino Cancer Research Network, directed by Amelie G. Ramirez, DrPH, Principal Investigator. Redes En Acción is funded by National Cancer Institute Grant Nos. U01 CA114657 and 1 U54 CA153511-01 and is headquartered at the Institute for Health Promotion Research at The University of Texas Health Science Center at San Antonio. For more information, visit www.redesenaccion.org.

Many of the patient navigator templates and examples provided throughout this manual stem from the Redes En Acción: National Patient Navigator Intervention Study, which tested patient navigation’s ability to decrease Latinas’ lag times from abnormal screening to confirmatory diagnosis and treatment initiation in San Antonio, Texas, and the local site of the Patient Navigator Research Program, a national program funded by the National Cancer Institute that is similarly testing patient navigation.
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How do you build/implement patient navigation?
Build your own patient navigator program by considering the right type of:

- Navigation model
- Navigator(s)
- Patient recruitment methods
- Latino demographics and culture
- Community resource directory
- Program reporting and monitoring

Now if you’re ready to build your program, check out these templates (page 37) and resources (page 38).
What is Patient Navigation?

Patient navigation is “the assistance offered to healthcare consumers (patients, survivors, families, and caregivers) to help them access and then chart a course through the healthcare system and overcome any barriers to quality care.”

**Navigation’s two key goals are to:**

- Reduce barriers to cancer care; and
- Ensure timely delivery of healthcare services.

A patient navigator intervention utilizes culturally competent, trained individuals to help cancer patients alongside standard care personnel (i.e., physicians, nurses, social workers), to reduce or eliminate cancer health disparities.
Why is Patient Navigation Needed?

Patient navigation aims to reduce cancer health disparities – “differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the United States.”

Some groups suffer disparities in cancer incidence and outcomes, compared to the majority. This is complicated by socioeconomic and cultural disparities in healthcare:

- Less education
- Lower income
- Less insurance
- Less access to healthcare
- Language barriers
- Cultural myths

These disparities can lead to inadequate screening and preventive care and result in delayed diagnosis of cancer, late or inadequate treatment and worse outcomes.

Latinos’ Tough Road

Many Hispanics/Latinos face a multitude of access barriers when seeking and receiving healthcare services. Because of such access barriers, like lack of health insurance coverage, lack of culturally and linguistically appropriate care, perceived and real discrimination and institutional racism, and lack of transportation to care, Hispanics/Latinos are more likely than are non-Hispanic whites to forego or delay receiving timely healthcare services for illnesses and injuries. This situation makes patient navigation a critical need.
How Did Patient Navigation Come About?

Dr. Harold Freeman of the Ralph Lauren Center for Cancer Care and Prevention in Harlem, N.Y., pioneered the concept and launched the first patient navigator program in 1990 to reduce cancer health disparities in predominantly African-American Harlem.

Based on the program’s success and Dr. Freeman’s advocacy, the national “Patient Navigator Outreach and Chronic Disease Prevention Act” was enacted in 2005.

Research funding then helped the National Cancer Institute and the Center for Medicaid and Medicare Services study patient navigation in sites across the U.S.

Rise of Patient Navigation in U.S.

Go [here](#) to see a detailed timeline on the unique rise of patient navigation in America. Along with Dr. Freeman, the American Cancer Society, the President’s Cancer Panel, and Former President George W. Bush all played key roles.
What are Typical Patient Navigation Services? Part 1

Patient navigators help patients feel secure that they’ll get needed treatment and won’t fall through the cracks in a healthcare system that may otherwise make them feel lost.

Navigators are trained to:
- Identify perceived or real barriers in cancer care
- Ensure patients’ abnormal screenings are followed up with cancer care
- Link patients, caregivers, and families with needed follow-up services
- Increase access to culturally appropriate, supportive care
- Communicate between healthcare providers, caregivers, and patients
- Direct patients to comprehensive resources
- Streamline patients’ appointments, paperwork
- Help patients fill out forms
- Identify financial aid options
- Maintain regular contact with patients through care
- Monitor patient progress

Q: How did a patient navigator help you, Mrs. Torres?

A: “The patient navigator helped me with transportation and she was there for me at the time of need. She got me helpful medical information when I couldn’t, she explained how the CareLink program worked, in which I continued with my medical care, she helped me schedule my appointments, she got me resources on clothing vouchers and food assistance, and she accompanied me to my surgery, which I really appreciate because I did not have anybody to go with me. I felt that I could call her and she would answer any question that I had. If I need help, I can call the patient navigator and she will direct me in the right direction. Before, I really didn’t know how to get around and people from the clinic didn’t have the answers that I needed.”
What are Typical Patient Navigation Services? Part 2

Patient navigators also work with medical and healthcare providers to enhance office operations and the care given to patients.

Navigators are trained to:

- Identify perceived or real barriers to cancer care in a healthcare setting
- Work with patients and providers to schedule appointments
- Communicate between providers, caregivers, and patients
- Coordinate services within the healthcare organization, with outside healthcare facilities, and within the community
- Coordinate clinical services within the healthcare organization and social services within the community.
- Work with providers to monitor patient progress

NOTE: Patient Navigation is not a substitute for medical care or patient healthcare planning and monitoring. It always should be provided under the auspices of licensed medical providers within the healthcare organization.

Q: How did a patient navigator help your clinic, Dr. Alexander Miller?

A: “I believe the value of the patient navigator is to allow the patient to recognize an advocate and a friend while going through the difficult process of obtaining healthcare. Large healthcare organizations are often impersonal and confusing. The patient navigator is able to personalize care, explain it and organize it for many patients and thereby reduce their anxiety and distress.”
Are You Ready for Patient Navigation?

Now you know a lot about patient navigation, its history and how a navigator can help patients and health organizations, as well as reduce cancer health disparities.

Enter Section 2 to weigh six steps in your consideration of whether patient navigation is the right fit for your organization.

Or if you already know it’s right, go to Section 3 for a detailed guide for developing and implementing your own patient navigation program.
Is Patient Navigation Right for Your Organization?

Different types of patient navigation are available to address differences in healthcare settings, the needs and characteristics of different special population groups and an organization’s available resources.

Organizations that want to know if a patient navigator program is right for them should take the following quick six-step review to shape their decision.

### Six-Step Decision Tool for Navigation

1. Assessing Organizational Need
2. Budgeting
3. Training
4. Developing Internal Systems
5. Developing Navigation Support Materials
6. Navigation Accountability
Step 1: Assessing Organizational Need

Conduct a needs assessment of the organization and cancer health disparities among clients. Gather state, county and clinical data on cancer incidence and mortality.

Also consider the following in-clinic data:

- Clinic flow of patients by day, week, month and year
- Abnormal cases in a given year by site, race and ethnicity
- Cancer cases in a given year by site, race and ethnicity
- Number of cases lost to follow-up that required medical treatment
- Percentage of uninsured patients
- Percentage of monolingual patients
Step 2: Budgeting

A navigator’s education and skill level are main determinants of the cost of patient navigation. Education, a typical gauge for salary, can range from a peer educator recruited from the community and trained in a clinical setting to an oncology research nurse with a graduate degree.

A small initial cost also may be needed to coordinate patient navigation services with existing healthcare practices of other clinical support staff (i.e., physicians, nurses, accounting, reception and scheduling).

Other expenses include supplies, materials and equipment (i.e., computer, telephone/cell phone, patient education, outreach materials, printing costs, etc.)

Common Types of Navigators and Educational Requirements

It’s difficult to categorize types of navigators by education level, but here is a general glimpse into the issue:

- **Promotora/Community Health Worker (CHW)**: High-school education or equivalent, some may have a CHW certification/associate degree
- **Patient Navigator**: At a minimum, undergraduate degree in social sciences (i.e., psychology, social work, health education)
- **Clinical Patient Navigator**: Licensed Registered Nurse (RN)

**Typical Costs Involved in Patient Navigation**

- Navigator’s salary
- Computer
- Cell phone
- Mileage reimbursement for navigator
- Office supplies

Educational materials (many materials are available free by request or may be downloaded from accredited and recognized organizations. Check out some resources [here](#).)
Step 3: Navigator Training

The needs, resources and structure of a healthcare organization determine the necessary education and skill level of the patient navigator. Regardless of the navigator’s background and experience, some training is required. Organizations should consider these questions:

• Who is qualified to train the patient navigator(s)?
• How will the effectiveness of training be measured?

Here are training resources from several U.S. patient navigator programs:

• Harold P. Freeman Patient Navigator Institute [click here]
• Patient Navigation in Cancer Care Tool Kit: Guiding Patients to Quality Outcomes [click here]
• Colorado Patient Navigation Training [click here]
• Breast Health Patient Navigator Program Resource Kit by the Healthcare Association of New York State (HANYS) – [click here]
• Colonoscopy Patient Navigator Program: Orientation Manual – [click here]
• LIVESTRONG Cancer Survivorship Training Program for Promotores (in Spanish) [click here]
Step 4: Developing Internal Systems

Patient navigation will require coordination and planning with appropriate departments and support staff.

Navigators will need to learn administrative procedures (i.e., how scheduling occurs and how patients receive healthcare communications, such as screening diagnostic referrals, test results, consultation, payment options and medication questions).

New clinic procedures may be required to accommodate the roles and responsibilities of the patient navigator.
Step 5: Developing Navigation Support Materials

A key source of information that each patient navigation program should have is a community resource directory, which is unique to each community.

Compiling the directory is a navigator’s first task. Depending on the needs and interests of the healthcare organization and its patient population, promotional materials may be useful, such as a patient brochure explaining a navigator’s benefits.

Healthcare organizations also may want to promote their patient navigation services via posters, newsletters, newspaper articles or advertisements, TV news, radio talk show interviews or the Internet.

A sample community resource directory from the San Antonio patient navigator program can be found here.
Step 6: Navigation Accountability

All parts of a healthcare organization must be accountable to the resources it consumes and the benefits it produces to the organization and its clients.

A patient navigation program should have a system for collecting data that reflects the quality and quantity of services it provides (see Templates for a series of forms and surveys to help determine the potential outcomes of a patient navigator program).

Depending on the needs of the healthcare organization and the resources for monitoring patient navigation, data collection should enable a host organization to identify navigation effects, provide diagnostics for problem resolution, guide institutional decision-making relating to healthcare services and patient satisfaction with healthcare and patient navigation.
Is Patient Navigation Right for Your Organization?

Now you’ve considered how a patient navigator program can fit into your organization.

If it’s right for you, go to Section 3 for a detailed guide for developing and implementing your own patient navigation program.
Thanks for Choosing Patient Navigation

Now you need to build and implement a patient navigation program to help improve patient health and reduce cancer health disparities in your area.

Following are several tools you can use to help you achieve this goal.
Types of Patient Navigation Models

First, you'll select a type of patient navigator program. There are several successful models, based on navigator skills and educational backgrounds:

- **Promotora/community health worker (CHW)**
- Social worker or college graduate with a health education or related major
- Nurse (registered, research, oncology)

Healthcare organizations should assess the best type of patient navigation model based on institutional needs and resources. The navigator’s education level does not make one model better than the others. Regardless of education level, a properly trained patient navigator matched to the needs of the organization should provide services that deliver the same cancer disparities reducing outcomes.

**Navigator models**

Our team has used a college graduate navigator with a health education major. The navigator worked together with a nurse practitioner to identify, refer and recruit patients to a research project.

Another type of model we have used is a **promotora**, a lay health worker trained to promote health among her community peers. Our promotora (pictured here) helps educate local Latinas about cancer awareness.
When Does Patient Navigation Begin?

Each healthcare organization’s needs and resources determine the inception of navigation. Navigation services could begin with the promotion of screening services in the community or within clinical settings triggered by an abnormal screening result.

How Long Does it Last?

Patient navigation typically continues through patient care until the resolution of the patient’s condition or in the case of patients diagnosed with cancer, it will continue until the completion of treatment or until the patient no longer desires navigation services.
Identifying Patients

The process of identifying patients will vary depending on your organization’s patient care practices. A well-defined referral system should be developed and followed.

What is most important is that all healthcare providers (i.e., physician, nurse, or physician assistant) work together as a team with the patient navigator to identify patients. For instance, if navigation is solely clinic-based and is triggered by an abnormal screening result, healthcare provider(s) should:

- Discuss abnormal findings with the patient before any contact with navigator
- Follow a standard procedure at the initiation of each patient navigation

Medical referrals can help

Our team’s local project identified patients by pairing a patient navigator with a nurse practitioner at a clinic. They worked together to refer and recruit participants. The navigator then recruited Latinos by having the healthcare professionals introduce the project to the patient and encourage the patient to participate. The professionals then introduced the patients to the patient navigator. This was more successful than having the patient navigator introduce herself/himself without a proper referral from a medical authority.
Latino Considerations: Demographics

The Latino population, already the nation’s largest minority group, is the fastest-growing segment of the population. Latinos will triple in size and will account for most of the nation’s population growth through 2050. Hispanics will make up 29% of the U.S. population in 2050, compared with 14% in 2005.4

There’s a great need for patient navigators to address the needs of Latino cancer survivors.5

Patient navigation addresses barriers...

- Financial
- Transportation
- Language
- Culture/race/age biases
- Healthcare system
- Fear

Without it, barriers remain and patients...

- Miss appointments
- Delay cancer care until they are very sick
- Seek alternative treatment
- Don’t receive adequate medical treatment
Latino Considerations: Culture

A major factor when working with Latino populations is considering their culture.

The Latino population is often best described as a mosaic of cultures. Hispanic subgroups reflect differences in ethnicities, cultures, and origin. Subgroups include Mexican, Puerto Rican, Cuban, Central and South American or Spanish origin. Each of these subgroups is unique and distinct.

Following are some cultural issues prominent for Latinos:

- **Familismo (Familism)** is the preference for maintaining a close connection to the family.
  
  Latinos, in general, are socialized to value close relationships, cohesiveness, and cooperativeness with other family members. These close relationships are typically developed across immediate and extended family members, as well as close friends of the family.

- **Personalismo (Personalism)** is the valuing and building of interpersonal relationships.
  
  Personalismo encourages the development of warm and friendly relationships, as opposed to impersonal or overly formal relationships.

- **Respeto (Respect)** implies deference to authority or a more hierarchical relationship orientation.
  
  Respeto emphasizes the importance of setting clear boundaries and knowing one’s place of respect in hierarchical relationship. This may be displayed through the family’s relationship with the provider and in their openness to discussing family relationships. This dynamic may create a situation where the relationship is not seen as a partnership. Rather, the family may defer to the professional and not express disagreement.

- **Religion and Spirituality** is the critical role that faith plays in the everyday life of most Latinos.
  
  Most Latinos are Christians, with the majority belonging to the Roman Catholic Church. However, different groups may have different faith affiliations. As it does for many people, religion offers Latinos a sense of direction in their lives and guidance in the education and raising of their children. Depending on where they are from, they may also seek medical or mental healthcare from alternative healthcare providers, such as curanderos, sobadores, and espiritistas.
Latino Considerations: Language

Language is one of the biggest barriers to obtaining good quality healthcare.

Having a fully bilingual and bicultural patient navigator can bridge the language gap and offer the cultural sensitivity needed to work with the Latino population.

Latino language patterns rely heavily on their nativity (domestic or foreign-born), level of acculturation and assimilation, and educational attainment. Language is so essential that it has created a shared sense of ethnicity among Latino subgroups throughout the U.S.

Language can be a complex issue. Patient navigators are encouraged to become familiar with the population that they will be working with. Some Latinos who have lived in the U.S. for several generations may only speak English. Others may mix English and Spanish (“Spanglish”). Recent immigrants may mostly be monolingual, but their children are often bilingual and may be more comfortable speaking English. There is even a smaller group of Latinos that do not speak Spanish but rather their own native dialects.

It’s important to be mindful of health literacy issues among Latinos. Just because a person is fully fluent in Spanish, it does not mean that he/she can read complex consent forms and study documents, or even write or sign their names. If this is the case, individuals often feel embarrassed and may be more reluctant to participate.
Patient Navigator Roles & Responsibilities: Part 1

Patient navigators fulfill various roles and have multiple responsibilities.

The ultimate patient navigator role is to guide patients through the healthcare system to overcome barriers and ensure the timely delivery of healthcare services. To do so, navigators must possess certain qualities.

Patient Navigator Qualities

Patient navigators are a very special group of professionals. They must possess certain professional skills as well as various personal characteristics.

**Professional**
- Responsible
- Organized
- Resourceful
- Reliable
- Positive-minded
- Team player

**Personal**
- Caring
- Friendly
- Warm
- Trustworthy
- Patient
- Dedicated
Patient Navigator Roles & Responsibilities: Part 2

Establishing a Relationship with the Patient

It is imperative that the patient navigator establish a nurturing, positive relationship with the patient from the beginning.

A first step in establishing a sound relationship starts with a discussion about:

- Patient navigator roles and responsibilities
- Patient navigator limitations
- Protection of patient privacy
- Expectations from the patient regarding the navigation process

How navigators can build a strong rapport with patients:

- Introduce yourself in a professional, warm and friendly manner.
- Ask the patient how he or she would like to be addressed (i.e., Mr/Mrs. Garza, Señor(a) Garza, Doña Lupita).
- If speaking in Spanish, ask if the patient would rather use formal (usted) or informal (tu) Spanish.
- Explain your role and limitations.
- Give ample opportunities for the patient to ask questions.
- Follow up promptly with the patient, via mail or telephone, to establish confianza (a trusting relationship).
- Provide a number where patients can reach you (business card).
Patient Navigator Roles & Responsibilities: Part 3

Communication

Navigators should keep three important areas of communication in mind:

Empathy
- Exude a shared experience with the patient (i.e., same culture, language)
- Sincerely interact so that patient feels he/she has been seen, heard and accepted

Engagement
- Make a connection that continues throughout the encounter and sets the stage for a developing partnership

Education
- Determine what the patient already knows to ask questions, assess concerns
- Provide information and communicate understanding to the patient to decrease patient’s perceived uncertainty and anxiety
- Address patient questions:
  - What will be done to me?
  - Will it hurt?
  - Who can help me?
Patient Navigator Roles & Responsibilities: Part 3 (continued)

Communication

Three more important areas of communication to keep in mind are:

Enlistment

• Encourage patient to work together with you on a plan to overcome barriers

Cultural Competency

• Communicate fluently in patient’s preferred language

• Understand or have familiarity with the patient’s socio-economic background

• Be familiar with environmental barriers confronting the patient

Negative Communication

• Avoid negative comments

• Avoid judgmental statements

• Do not discuss patient records/history outside of the navigation team

More Info

For additional training on health literacy, cultural competency and limited English proficiency and how to improve patient-provider communication, please go here.
Patient Navigator Roles & Responsibilities: Part 4

Know Your Cancer Basics

Patient navigators need basic knowledge about cancer and cancer health disparities. In cancer, abnormal cells grow uncontrollably and can invade other tissues.

Of course, working within a clinical setting, navigators have the opportunity to refer medical questions to those with formal health training (i.e., physicians, nurses).

So, although you don’t have to be a cancer expert, it helps to know about:

- Cancer prevention
- Cancer genetics
- Cancer causes and risk factors
- Screening/testing to detect cancer
- Cancer treatment
- Coping with cancer
- Cancer clinical trials
- Cancer survivorship

The American Cancer Society has a wealth of information on cancer topics.

Latino Cancer

While Latinos generally have lower cancer incidence compared to Non-Hispanic whites, they also have higher mortality rates (as they may delay treatment due to fear, lack of health insurance, etc.).

The most commonly diagnosed cancers among Hispanic women include:\n- Breast
- Colon/rectum
- Lung

The most commonly diagnosed cancers among Hispanic men include:\n- Prostate
- Colon/rectum
- Lung

Other common cancers among Latinos include cervical, gallbladder, stomach, pancreas and liver.
Patient Navigator Roles & Responsibilities: Part 5

**Patient Confidentiality and Data Security**

Patient navigators must become familiar with the *Health Insurance Portability and Accountability Act* (HIPAA), patient confidentiality and security issues involving patients’ medical data.

The U.S. Department of Health and Human Services issued the Privacy Rule to implement the requirement of HIPAA in 1996. Before collecting any data, research study protocols must be approved by corresponding Institutional Review Boards (IRB).

While patient navigation may not be perceived as a research activity, program operations should be familiar with all state or federal laws that may impact patient privacy practices.

**Protecting Patient Privacy**

Our team’s patient navigator received extensive training on privacy issues, patient confidentiality, and HIPAA regulations through our Institutional Review Board as part of her preparation for the patient navigator project.

For more information on key elements of the Privacy Rule, go [here](#).
A key tool of every patient navigation program is a comprehensive Community Resource Directory that concisely describes all community, state, federal and private resources that the navigator might refer to in performing navigation duties.

The Community Resource Directory includes a listing of existing resources available to patients. The list includes names of organizations, contact persons, addresses, telephone numbers, Web sites and a brief description of the services offered by each organization.
Community Resource Directory: Part 2

Here are some tips to build and update the directory. You will want to build an electronic database to store directory information, so it can be easily updated and distributed.

To gather information for the directory:
- Search the Internet.
- Contact local community collective organizations (i.e., the United Way, American Cancer Society) and review their resources and relevant information.

Once you have the information:
- Alphabetically organize information into categories or theme areas.
- Contact each directory group for accuracy (thus also introducing the navigator program to those groups, who could then promote the program).
- Develop a partnership agreement with certain community resources to strengthen collaborations and solidify partnerships.

In our San Antonio project, thanks to our Community Resource Directory, the patient navigator was easily able to refer patients to medical services within and outside the healthcare system. The directory also enabled the navigator to refer patients to social services. Social-service resources may include but are not limited to:
- Paying utilities
- Low-income living
- Free English as a Second Language (ESL) classes
- How to qualify for Medicaid services
- Free back-to-school supplies for students
- Available shelters for abused women

Find our directory here.
Patient Navigation Reporting

Regular scheduled monthly or quarterly meetings among the navigation team should occur.

**Meetings should:**
- Review navigation progress to date
- Review clinical operations impacted by navigation
- Discuss problems, identify solutions
- Review data collected to date
- Discuss additional training opportunities
Every navigation program should be closely monitored to identify and resolve problems and provide data that confirms achievement of navigation goals and objectives.

These data will be summarized and presented to the healthcare organization’s management group on a regular schedule.

**Evaluation should try to answer these questions/concerns:**

- Is patient navigation functioning according to its goals and objectives?
- Are the monitoring instruments being used properly?
- Are all the essential data being captured (either from the patient and/or from the medical charts)?
- Are the data being entered promptly and properly?
- Are the data being summarized properly and reported regularly?
- Is the Community Resource Directory being updated promptly?
- Is the healthcare organization satisfied with the effectiveness of the navigation program?
Congratulations!

At this point you know a great deal about patient navigation, its benefits and how you can weave it into your organization.

We wish you luck making it happen!

Check out these templates and resources to help you along the way.
## Templates

### Patient Navigator Template Tools

- **Implementation Tools** – [click here](#)
  - Patient Navigator Job Description

- **Patient Navigator Tools**
  - Community Resource Directory – [click here](#)

- **Patient Data Collection Tools** – [click here](#)
  - Recruitment Letters (English & Spanish)
  - Consent Forms (English & Spanish)
  - Patient Contact Sheet
  - Patient Navigation Plan
  - Patient Baseline Surveys (English & Spanish)
  - Patient Post Surveys (English & Spanish)
  - Breast Clinical Data Form (PNRP)
  - Comorbidity Form (PNRP)
  - Key Informant Survey
  - Refusal Surveys (English & Spanish)
Patient Navigation Resources

Training Resources:

- Harold P. Freeman Patient Navigator Institute – [click here]
- Patient Navigation in Cancer Care Tool Kit: Guiding Patients to Quality Outcomes [click here]
- Colorado Patient Navigation Training – [click here]
- Breast Health Patient Navigator Program Resource Kit by the Healthcare Association of New York State (HANYS) – [click here]
- LIVESTRONG Cancer Survivorship Training Program for Promotores (in Spanish) [click here]

Educational Resources for Navigators/Patients (English & Spanish)

- National Cancer Institute – [click here]
  Help with ordering: 1-800-4-CANCER
- American Cancer Society – [click here]
- Centers for Disease Control and Prevention – [click here]
- Cancer Care – [click here]
- Susan G. Komen for the Cure – [click here]
- LIVESTRONG – [click for English], [click for Spanish]
References


