Patient Navigation Guidelines
Cancer Screening, Diagnosis and Treatment

People seldom refuse help, if one offers it in the right way. --A.C. Benson

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**Definition of Patient Navigation**

In 1995 Dr. Harold P. Freeman first described patient navigation as a means for improving access to recommended cancer screening services, follow-up, diagnosis and treatment in medically underserved populations.\(^1\) Patient navigation is a process by which trained individuals proactively guide patients through and around barriers in a complex cancer care system to decrease fragmentation of care and to coordinate services.\(^2\)

**The Principles of Patient Navigation\(^3\)**

1. **Patient navigation is a patient-centric healthcare service delivery model.** The focus of navigation is to promote the timely movement of an individual patient through an often complex healthcare continuum. An individual's journey through this continuum begins in the neighborhood where he or she lives, to a medical setting where an abnormality is detected, a diagnosis is made, and then treatment rendered. The journey continues from rehabilitation and survivorship to the end of life.

2. **Patient navigation serves to virtually integrate a fragmented healthcare system for the individual patient.** As patient care is so often delivered in a fragmented manner, particularly related to those with chronic diseases, patient navigation has the potential of creating a seamless flow for patients as they journey through the care continuum. Patient navigation can be seen as the guiding force promoting the timely movement of the patient through a complex system of care.

3. **The core function of patient navigation is the elimination of barriers to timely care across all segments of the healthcare continuum.** This function is most effectively carried out through a one-on-one relationship between the navigator and the patient.

4. **Patient navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers.** Navigators should be integrated into the healthcare team to promote maximum benefit for the individual patient.

5. **Delivery of patient navigation services should be cost-effective and commensurate with the training and skills necessary to navigate an individual through a particular phase of the care continuum.**

6. **The determination of who should navigate should be determined by the level of skills required at a given phase of navigation.** There is a spectrum of navigation extending from services that may be provided by trained lay navigators to services that require navigators who are professionals, such as nurses and social workers. Another consideration to take into account is that healthcare providers should ideally provide patient care that requires their level of education and experience and should not be assigned to duties that do not require their level of skills.

7. **In a given system of care there is the need to define the point at which navigation begins and the point at which navigation ends.**

8. **There is a need to navigate patients across disconnected systems of care, such as primary care sites and tertiary care sites.** Patient navigation can serve as the process that connects disconnected healthcare systems.

9. **Patient Navigation systems require coordination.** In larger systems of patient care, this coordination is best carried out by assigning a navigation coordinator or champion who is responsible for overseeing all phases of navigation activity within a given healthcare site or system. It is important to distinguish a system of patient navigation from the patient navigator(s) who work within the system.

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\(^1\) Freeman HP, Muth BJ, Kerner JF. Expanding access to cancer screening and clinical follow-up among the medically underserved. Cancer Pract. 1995; 3:19-20


The Goal of Patient Navigation:
The goal of patient navigation is to save lives from cancer by:
- Providing outreach for screening
- Eliminating barriers to care
- Ensuring timely delivery of services

Patient Navigation Attributes
The Patient Navigator assists a patient in obtaining quality health care from screening through diagnosis and treatment and incorporates the following principles into their practice:
- Respect
- Patient Safety
- Confidentiality
- Compassion
- Patient Empowerment
- Cultural competence

Patient Navigation Hypothesis:
Patients receiving patient navigation interventions will:
- Receive more timely diagnostic evaluations after an abnormal screening
- Receive more timely treatment after positive confirmation of disease
- Experience greater satisfaction with the health care system
- Have a higher rate of screening after referral

Patient Navigation Expected Outcomes:
- Patient/family satisfaction
  - Decreased worry and frustration
  - Increased sense of partnership with professionals
  - Improved satisfaction with team communication
- Staff satisfaction
  - Improved communication and coordination of care
  - Improved efficiency of care
  - Elevated challenge and professional role
- Improved patient outcomes
  - Access to quality health care
  - Increase in access to needed resources
  - Enhanced self-management skills
- Improved systems outcomes
  - Decreased duplication of services
  - Decreased fragmentation of care
  - Improved communication and coordination

Patient Navigation Boundaries:
- Always work within the treatment recommendations of the provider. The patient navigator should never give any recommendations contrary to the recommendations of the provider.
- Boundaries are important because the patient navigator is in a position of influence and the patient is in a vulnerable position. Over involvement with a patient can be draining on the patient navigator and can interfere with the important tasks of the job.
- Assess cultural ideas and prejudices. Know your community.
- Some behaviors that can lead to blurry boundaries and should be avoided are:
  - Self-disclosure;
  - Giving or receiving gifts;
  - Developing friendships;
  - Physical contact.
- Some health practices to establish professional boundaries are:
  - Set limits on patient interactions (Remember that your involvement is temporary)
  - Encourage self-reliance/independence
  - Use your supervisor to check yourself
  - Address the problem as soon as you recognize it.
Patient Navigation Across the Health Care Continuum

Patient navigation is a healthcare delivery support system with the principle function of eliminating barriers to timely delivery of health care for individual patients across the healthcare continuum. Patient navigators may be assigned specific phases of the patient navigation model, which may include prevention, detection, diagnosis, treatment, and survivorship through the end of life. In larger systems of health care, there is a need to oversee and coordinate the various phases of activity of patient navigators across the healthcare continuum.\(^4\)

![Patient Navigation Across The Health Care Continuum](image)

Outreach Patient Navigation (Outreach to Screening)

**Scope:**
Patient navigation at this level begins with outreach to clinic patients who are eligible for preventive screening and as defined by the clinic and ends with a completed screening.

**Objectives:**
- Increase preventive screenings.
- Build one-on-one rapport with the clinic patients.
- Provide education to patients about the importance of preventive screening.
- Identify barriers to accessing the health care system.
- Ensure that patients make it to the screening appointment.
- Track screening results.

**Activities:**
- **Identify** patients eligible for screening by:
  - Providing outreach to patients enrolled who are in need of cancer screening.
  - Reviewing daily schedule and/or pulled charts for patients meeting criteria.
  - Placing a referral or reminder in the chart for the physician to complete.
  - Providing education to referred patients on the importance of cancer screening and early detection.
- Obtain the patient’s consent to contact.

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Streamline appointments and paperwork:
- Assist patients with scheduling appointments when possible
- Fax referral to appropriate radiology/lab center
- Provide patients with information to prepare for the appointment
- Provide education to the patient on the screening procedure
- Provide directions to the radiology center/lab

Help decrease the patient’s fear and anxiety

Facilitate interaction and communication with clinic staff and screening providers

Assist patients with any state/charitable applications necessary to receive screening.

Follow-up with patients after referral as outlined below:
- If the scheduled appointment date is known, call patient 2 business days prior to the appointment as a reminder
- If appointment is to be scheduled by patient, call patient 7 business days after the clinic visit verify that appointment has been scheduled and to offer assistance if there are problems in scheduling.
- Patients not having an appointment scheduled by the 7th business day following the clinic appointment should be assessed for barriers to completing the testing, educated on the importance of completing the testing and contacted again at 30 and 60 days to check for adherence to recommendations. (A note should be placed in the medical record that the patient has not received recommended testing)
- When a patient has not been able to be contacted within 30 days (3 attempts to contact should be made on different dates and times) following the referral date, a letter should be sent to patient requesting that the patient contact the patient navigator and a copy of letter placed in patient’s medical record. The patient should be actively followed for an additional 30 days before closing the case.
- When a patient has not been able to be contacted within 30 days of following the clinic’s receipt of abnormal/incomplete screening results (3 attempts to contact should be made on different dates and times)1) Notify the PCP 2) Facilitate a letter to the patient signed by the PCP/Medical Director of Clinic (this letter should be sent by certified mail and regular mail) and place a copy of the letter in the patient’s medical record. 3) Actively follow the patient for an additional 30 days before closing the case.
- If results are not received within 14 days of the screening, a call should be placed to the screening center requesting that the results be sent to the clinic.
- **ALL SCREENING RESULTS MUST BE REVIEWED/SIGNED OFF BY THE DESIGNATED C PROVIDER**
  - When the results are normal the case may be closed
  - When the results are incomplete contact patient to determine if follow-up imaging/lab tests have been scheduled or completed. If this has not been done, assist the patient in scheduling additional testing.
  - When the results are abnormal refer the case to the diagnostic patient navigator for diagnostic follow-up.
  - Track contacts, interventions and outcomes.
  - Note any significant patient interactions in the patient’s medical record and alert the provider.

**Diagnostic Patient Navigation (Abnormal Screening to Diagnosis)**

**Scope:**

Patient navigation at this level begins with an abnormal screening/suspicious finding of a patient and ends with a definitive diagnosis (whether malignant or benign).

**Objectives:**
- Identify and assist patients in overcoming barriers to recommended follow-up diagnostic procedures and care.
- Assess patient’s knowledge and understanding of the recommended diagnostic procedure and its purpose.
- Provide education to patients and families.
- Move patients through a complex system in a timely manner.
- Ensure that patients make it to the diagnostic appointment.
- Track diagnostic results.
Activities

- Track patients who have had an abnormal screening.
- Build trust and rapport with the patient through one on one interaction.
- Provide education on surgical consults and biopsies.
- Assist the patient in preparing for appointments.
- Help to decrease the patient’s fear and anxiety.
- Assist with state/charity applications for diagnosis and treatment.
- Follow-up
  - Call patient 2 business days prior to consult/biopsy appointment as a reminder.
  - If appointment is to be scheduled by patient, call patient weekly to verify that appointment has been scheduled, answer questions or concerns and to assist if there are problems in scheduling.
  - Patients who are not willing to have an appointment scheduled should be 1) educated on the importance of diagnostic follow-up, 2) assessed for barriers to follow-up, and 3) assisted in overcoming identified barriers.
  - The provider must be notified of patients who are unwilling to have a follow-up appointment and the patient’s decision documented in the medical record.
  - When a patient has not been able to be contacted within 30 days of following the receipt of abnormal/incomplete screening or consult/biopsy results (3 attempts to contact should be made on different dates and times) 1) Notify the provider 2) Facilitate a letter to the patient signed by the Provider/Medical Director of Clinic (this letter should be sent by certified mail and regular mail) and place a copy of the letter in the patient’s medical record. 3) Actively follow the patient for an additional 30 days before closing the case.
  - If results are not received within 14 days, a call should be placed to the diagnostic testing site requesting that the results be sent to the clinic.
  - All results must be reviewed/signed off by the provider or a designated provider
    - When the results are (Normal/Benign) contact patient to review recommendations
    - When the results are (Abnormal/Malignant) refer the patient to Treatment Patient Navigation (Diagnosis to Treatment) for intensive follow-up.
  - Track contacts, interventions and outcomes.
  - Note any significant patient interactions in the patient’s medical record and alert the provider.

Treatment Patient Navigation (Diagnosis to Treatment Termination)

Scope:

Patient navigation at this level begins with a definitive diagnosis of cancer and ends with the completion of active treatment.

Objectives:

- Assess barriers to receiving recommended care and assist the patient in overcoming these barriers.
- Facilitate the communication among patients, family members and healthcare providers.
- Coordinate transitions of care between providers and sites.
- Ensure timely treatment for cancer patients.
- Ensure follow-up on all recommended procedures and treatment.
- Provide compassionate support.
- Assess patient’s understanding of medical problems and treatment options.
- Empower patient to make informed decisions on their health care through education and coaching.

Activities:

- Build trust and rapport with the patient through one-on-one interactions.
- Assist the patient in preparing for appointments.
- Assess patient’s best method of learning
- Provide education on coping with cancer, what to expect during chemotherapy and radiation, and dealing with the side effects of treatment.
- Identify resources for financial assistance, medication needs, home health care, transportation and other concerns.
- Refer patients to support groups, classes and other programs for information and support.
Help to decrease the patient’s fear and anxiety by listening and caring.

Assist with state/charity applications for treatment.

Follow-up:
- Call patient prior to treatment appointments as a reminder and to help patient prepare for the appointment.
- Assess for barriers to treatment and help provide solutions to address barriers.
- When a patient is unwilling to go to recommended treatment, **the Provider must be notified immediately. The patient navigator must document the patient’s decision not to comply with treatment recommendations in the medical record.**
- When a patient has not been able to be contacted within 2 weeks of a positive diagnosis (*3 attempts to contact should be made on different dates and times*), following the diagnosis date, 1) the Provider should be notified 2) a letter should be sent to patient and a copy of letter placed in patient’s medical record. *This letter should be sent by certified mail and regular mail 3) the patient should be actively followed for an additional 30 days before closing the case.*
- Track contacts, interventions and outcomes.
- Note any significant patient interactions in the patient’s medical record and alert the provider.
- Continue to assist patient with survivorship care plan or end of life issues and referral to hospice.

**Documentation*: 

It is the responsibility of the patient navigator to document pertinent information in the medical record. Documentation in the medical record should include but not be limited to the following:

- Barriers that may affect the patient’s ability to follow diagnosis and treatment recommendations, including but not limited to:
  - Fear
  - Cultural issues
  - Religious issues
  - Family issues
  - Language issues
  - Financial issues
  - Work issues

- Patient refusal to comply with clinical recommendations.

- Side effects of diagnostic testing or treatment identified by the patient.

- Physical or mental problems expressed by the patient.

- Inability of the patient to understand or confusion about recommended screenings, diagnostic tests and/or treatment.

- Inability to contact patient.

- Copies of all written communication to the patient.

*All significant issues should also be reported to the provider.*
Measuring Performance

Measuring performance is central to quality improvement because it provides information on current and past performance that can help guide future improvement efforts. In particular, performance measures can distinguish between good and substandard performance. Accordingly, the development and application of performance measurement is essential to improving the quality of care. It is one of the “first steps in the improvement process and involves the selection, definition, and application of performance indicator. Performance measurement, while not the only influence, can act as a force to promote certain issues and agendas. Performance measurement conveys the message of importance. Specifically, what is important is measured, while what is not measured is considered less important. By focusing people and resources on a particular aspect of an industry, performance measurement can be a driver of change and reform.

There are significant challenges associated with applying administrative or clinical data sources, no matter how “good” the measure is. Selecting measures and the purposes for which to use them should depend upon organizational or program needs. Implementation issues, including data availability and data quality, need to be addressed during the measure-selection process because the immediate goal is to produce usable information for quality improvement, public reporting, planning, and care redesign.

Data availability is an issue that must be addressed. Typical data sources include clinical data (e.g., medical record abstraction, laboratory data, pharmacy data, electronic medical record), survey data (e.g., patient experience with care, employee satisfaction), and operational data (e.g., licensure, ownership, staffing levels, type of staff). Each data source has its strengths and limitations. While clinical data is usually preferred by providers, it requires medical abstraction that is usually costly to collect. The primary benefit associated with the use of clinical data is the greater number of data elements that can be abstracted, resulting in enhanced measure definition, risk adjustment, and linkage to care processes. While there are efforts underway to expand and automate access to clinical data, automated data are not yet a reality.

Administrative data, on the other hand, are the most widely available source of information about hospital services, patient care, and patient outcomes. All hospitals generate administrative data as part of billing operations, and all payers have access to administrative data. These types of data have been shown to be useful in quality assessment and medical research, as well as for other measurement tasks such as screening for complications, identifying mortality rates, and tracking health system utilization. Like clinical data, administrative data also have limitations. Because administrative data are collected principally for billing and related administrative purposes, these data lack the depth of clinical detail that can be helpful in quality measurement; variations in coding practices may create challenges for quality evaluations; and there can be data validity issues. Since the concept of quality is multidimensional, a combination of measures derived from clinical and administrative data sources would offer a more complete picture of quality, at least in the immediate future.

Tips for Effective Measurement

Measurement should be used to speed improvement, not slow it down. Often, organizations get bogged down in measurement and delay making a change until they have collected enough data.

- Plot data over time.
  Improvement requires change, and change is, by definition, a temporal phenomenon. Much information about a system and how to improve it can be obtained by plotting data—on length of stay, volume, patient satisfaction—over time and observing trends and other patterns. Tracking a few key measures over time is the single most powerful tool a team can use.

- Seek usefulness, not perfection.
  Remember, measurement is not the goal; improvement is the goal. In order to move forward to the next step, a team needs just enough data to know whether changes are leading to improvement.

- Use sampling.
  Sampling is a simple, efficient way to help a team understand how a system is performing.

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5 http://www.ncbi.nlm.nih.gov/books/NBK2664/
6 http://www.healthychild.ucla.edu/First5CARediness/materials/siteInfra/IHIQualityImprovementResources.pdf
Integrate measurement into the daily routine.
Useful data are often easy to obtain without relying on information systems. Don’t wait two months to receive length of stay data from the information systems department. Develop a simple data collection form and make collecting the data part of someone’s job. Often, a few simple measures will yield all the information you need.

Use qualitative and quantitative data.
In addition to collecting quantitative data, be sure to collect qualitative data, which often are easier to access and highly informative. For example, in order to focus your efforts on improving patient and family satisfaction, ask patients and their families about their experience.

Types of measures:

- **Outcome Measures**
  Outcomes are products of one or more processes and the measures tell you whether changes are actually leading to improvement.

- **Process Measures**
  Processes are activities that act on an input from a supplier (patient navigator, healthcare provider, etc.) to produce an outcome for a customer (patient) Measuring the results of these process changes will tell you if the changes are leading to improved care for patients.

- **Balancing Measures**
  Use these measures to make sure that changes to improve one part of the system aren’t causing new problems in other parts of the system. Examples include patient and provider satisfaction surveys.

- **Structure Measures**
  Measure elements that evaluate an organization’s ability to provide care (available staff, qualifications/credentials)

- **Rate Based Measures**
  Rate based measures have a numerator (number of occurrences) and a denominator (population studied). They are used to determine when a specific threshold or variance is reached.
Glossary of Terms:

Alternative Healing: The use of herbs, aromatherapy, acupuncture, massage and other remedies that are not considered part of conventional (Western) healthcare treatments.

BCCDTP: The Breast and Cervical Cancer Diagnosis and Treatment Program was established in 1992 to provide breast cancer and cervical cancer diagnosis and treatment services to program eligible Maryland residents (COMAR 10.14.02 http://www.dsd.state.md.us/comar/10/10.14.02.03.htm).

BI-RADS Classification System\(^7\): The Breast Imaging Reporting and Data System (BI-RADS), developed by the American College of Radiology, provides a standardized classification for mammographic studies. This system demonstrates good correlation with the likelihood of breast malignancy. The BI-RADS system can inform family physicians about key findings, identify appropriate follow-up and management and encourage the provision of educational and emotional support to patients.

<table>
<thead>
<tr>
<th>Category</th>
<th>Diagnosis</th>
<th>Number of Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Incomplete</td>
<td>Your mammogram or ultrasound didn't give the radiologist enough information to make a clear diagnosis; follow-up imaging is necessary</td>
</tr>
<tr>
<td>1</td>
<td>Negative</td>
<td>There is nothing to comment on; routine screening recommended</td>
</tr>
<tr>
<td>2</td>
<td>Benign</td>
<td>A definite benign finding; routine screening recommended</td>
</tr>
<tr>
<td>3</td>
<td>Probably Benign</td>
<td>Findings that have a high probability of being benign (&gt;98%); six-month short interval follow-up</td>
</tr>
<tr>
<td>4</td>
<td>Suspicious Abnormality</td>
<td>Not characteristic of breast cancer, but reasonable probability of being malignant (3 to 94%); biopsy should be considered</td>
</tr>
<tr>
<td>5</td>
<td>Highly Suspicious of Malignancy</td>
<td>Lesion that has a high probability of being malignant (&gt;= 95%); take appropriate action</td>
</tr>
<tr>
<td>6</td>
<td>Known Biopsy Proven Malignancy</td>
<td>Lesions known to be malignant that are being imaged prior to definitive treatment; assure that treatment is completed</td>
</tr>
</tbody>
</table>

BRCA1 and BRCA2\(^8\): BRCA1 and BRCA2 are human genes that belong to a class of genes known as tumor suppressors. In normal cells, BRCA1 and BRCA2 help ensure the stability of the cell’s genetic material (DNA) and help prevent uncontrolled cell growth. Mutation of these genes has been linked to the development of hereditary breast and ovarian cancer.

The names BRCA1 and BRCA2 stand for breast cancer susceptibility gene 1 and breast cancer susceptibility gene 2, respectively.

A woman's risk of developing breast and/or ovarian cancer is greatly increased if she inherits a deleterious (harmful) BRCA1 or BRCA2 mutation. Men with these mutations also have an increased risk of breast cancer. Both men and women who have harmful BRCA1 or BRCA2 mutations may be at increased risk of other cancers.

Genetic tests are available to check for BRCA1 and BRCA2 mutations. A blood sample is required for these tests, and genetic counseling is recommended before and after the tests.

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\(^7\) Margaret M. Eberl, MD, MPH, Chester H. Fox, MD, Stephen B. Edge, MD, Cathleen A. Carter, PhD and Martin C. Mahoney, MD, PhD, FAAFP. BI-RADS Classification for Management of Abnormal Mammograms The Journal of the American Board of Family Medicine 19:161-164 (2006)

\(^8\) http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA
Breast Biopsy:

- **Needle Biopsy:** Needle biopsy uses a hollow needle to remove samples of tissue or cells from the breast. These samples are then studied under a microscope to see if they are cancerous. If they are, then more tests will be done to help plan treatment. Needle biopsies can be used to study lumps that can be felt (palpable masses) and suspicious areas that can only be seen on a mammogram or other imaging tests (non-palpable masses). There are two types of needle biopsies: core needle biopsy and fine needle aspiration.
  
  - **Core needle biopsy** uses a thin, hollow needle to remove tissue from the breast. It can be used on suspicious areas that can be felt (palpable masses) and those that can only be seen on a mammogram or other imaging test (nonpalpable masses). Because it is accurate and does not involve surgery, it is often the preferred biopsy method.
  
  - **Fine needle aspiration (also known as fine needle biopsy)** is a needle biopsy that removes cells rather than tissue from an abnormal area in the breast. The needle used is thinner than in core needle biopsy. Fine needle aspiration is only used for suspicious areas that can be felt (palpable masses).

- **Surgical Biopsy:** In most biopsies, the entire suspicious area (plus some nearby normal tissue) is removed from the breast. If the area is too large to remove fully, only part of the area will be taken out. The tissue that is removed is tested for signs of cancer.
  
  - **Excisional Biopsy:** In an excisional biopsy, the whole abnormal area, plus a layer of nearby normal tissue, is removed.
  
  - **Incisional Biopsy:** In an incisional biopsy, only part of the tumor is removed. This procedure is only done when a tumor is too large to be removed with an excisional biopsy or when a needle biopsy is not possible. Excisional biopsy may be used for non-palpable masses (those that cannot be felt and can only be seen on a mammogram). Before surgery, a procedure called wire-localization or needle-localization will be done. During this procedure, a radiologist uses a mammogram or ultrasound image as a guide to insert a very thin wire into the suspicious area of the breast. The surgeon then uses this wire to find the area during surgery.

Breast MRI: Magnetic resonance imaging (MRI) of the breast — or breast MRI — is a test used to detect breast cancer and other abnormalities in the breast. A breast MRI captures multiple pictures of the breast. Breast MRI images are combined, using a computer, to generate detailed pictures. Breast MRI usually is performed when the doctor needs more information than a mammogram, ultrasound or clinical breast exam can provide. In certain situations, such as when a woman has a very high risk of breast cancer, breast MRI may be used as a screening tool for detecting breast cancer.

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9 http://ww5.komen.org/BreastCancer/Biopsies.html
10 http://www.mayoclinic.com/health/breast-mri/MY00300
Breast Cancer Staging\(^\text{11}\): Cancers with similar stages tend to have a similar outlook and thus are often treated in a similar way. Stage is expressed in Roman numerals from stage I (the least advanced stage) to stage IV (the most advanced stage). Non-invasive cancer is listed as stage 0.

**Stage 0:** This is ductal carcinoma in situ (DCIS), the earliest form of breast cancer. In DCIS, cancer cells are still within a duct and have not invaded deeper into the surrounding fatty breast tissue. Lobular carcinoma in situ (LCIS) is sometimes also classified as stage 0 breast cancer, but most oncologists believe it is not a true breast cancer.

**Stage IA:** The tumor is 2 cm (about 3/4 of an inch) or less across and has not spread to lymph nodes or distant sites.

**Stage IB:** The tumor is 2 cm or less across (or is not found) with micrometastases in 1 to 3 axillary lymph nodes (the cancer in the lymph nodes is greater than 0.2mm across and/or more than 200 cells but is not larger than 2 mm). The cancer has not spread to distant sites.

**Stage IIA:** One of the following applies:
- The tumor is 2 cm or less across (or is not found) and has spread to 1 to 3 axillary lymph nodes, with the cancer in the lymph nodes larger than 2 mm across.
- The tumor is 2 cm or less across (or is not found) and tiny amounts of cancer are found in internal mammary lymph nodes on sentinel lymph node biopsy.
- The tumor is 2 cm or less across (or is not found) and has spread to 1 to 3 lymph nodes under the arm and to internal mammary lymph nodes (found on sentinel lymph node biopsy).
- The tumor is larger than 2 cm across and less than 5 cm but hasn't spread to the lymph nodes.
- The cancer hasn't spread to distant sites.

**Stage IIB:** One of the following applies:
- The tumor is larger than 2 cm across and less than 5 cm across. It has spread to 1 to 3 axillary lymph nodes and/or tiny amounts of cancer are found in internal mammary lymph nodes on sentinel lymph node biopsy.
- The tumor is larger than 5 cm across but does not grow into the chest wall or skin and has not spread to lymph nodes.
- The cancer hasn't spread to distant sites.

**Stage IIIA:** One of the following applies:
- The tumor is not more than 5 cm across (or cannot be found). It has spread to 4 to 9 axillary lymph nodes, or it has enlarged the internal mammary lymph nodes.
- The tumor is larger than 5 cm across but does not grow into the chest wall or skin. It has spread to 1 to 9 axillary nodes, or to internal mammary nodes.
- The cancer hasn't spread to distant sites.

**Stage IIIB:** The tumor has grown into the chest wall or skin, and one of the following applies:
- Cancer has spread to 10 or more axillary lymph nodes.
- Cancer has spread to the lymph nodes under the clavicle (collar bone).
- Cancer has spread to the lymph nodes above the clavicle.
- Cancer involves axillary lymph nodes and has enlarged the internal mammary lymph nodes.
- Cancer has spread to 4 or more axillary lymph nodes, and tiny amounts of cancer are found in internal mammary lymph nodes on sentinel lymph node biopsy.
- The cancer hasn't spread to distant sites.

**Stage IIIC:** The tumor is any size (or can't be found), and one of the following applies:
- Cancer has spread to 10 or more axillary lymph nodes.
- Cancer has spread to the lymph nodes under the clavicle (collar bone).
- Cancer involves axillary lymph nodes and has enlarged the internal mammary lymph nodes.
- Cancer has spread to 4 or more axillary lymph nodes, and tiny amounts of cancer are found in internal mammary lymph nodes on sentinel lymph node biopsy.
- The cancer hasn't spread to distant sites.

**Stage IV:** The cancer can be any size and may or may not have spread to nearby lymph nodes. It has spread to distant organs or to lymph nodes far from the breast. The most common sites of spread are the bone, liver, brain, or lung.

\(^\text{11}\) [http://www.cancer.org/docroot/CRI/content/CRI_2_4_3X_How_is_breast_cancer_staged_5.asp?sitearea=](http://www.cancer.org/docroot/CRI/content/CRI_2_4_3X_How_is_breast_cancer_staged_5.asp?sitearea=)
Breast Cysts\textsuperscript{12}: are fluid-filled sacs that often feel like soft grapes. These can sometimes be tender, especially just before a menstrual period. Cysts may be drained in the doctor’s office. If the fluid removed is clear or greenish, and the lump disappears completely after it is drained, no further treatment is needed. If the fluid is bloody, it is sent to the lab to look for cancer cells. If the lump doesn’t disappear, or recurs, it is usually removed surgically.

Breast Density\textsuperscript{13}: The term breast density has been used to describe the features of the breast tissue as visualized from a mammographic image. On a film-screen mammogram, the stromal and epithelial tissues of the breast appear as shades of gray to white due to the attenuation of the X-rays. In contrast, the fat within the breast is more radiolucent and much darker in appearance on the mammogram. The visual appearance of these different tissues on a mammogram has been classified both qualitatively and quantitatively as a way to describe breast density.

Breast Pain\textsuperscript{14} (mastalgia) is a common type of discomfort among women — affecting as many as seven in 10 women at some point in their lives. About 10 percent of women have moderate to severe breast pain more than five days a month. In some cases, severe breast pain lasts throughout the menstrual cycles. Postmenopausal women can experience breast pain, but the symptom occurs more frequently in younger, premenopausal women and perimenopausal women. When it's severe, breast pain can have a major impact on daily activities, work and relationships. Breast pain alone rarely signifies breast cancer. Still, if unexplained breast pain persists, causes worry about breast cancer or otherwise disrupts life, the patient should get checked by a doctor.

Most cases of breast pain are classified as either cyclic or noncyclic. Each type of breast pain has distinct characteristics.

Cyclic breast pain:
- Clearly related to the menstrual cycle
- Described as dull, heavy or aching
- Often accompanied by breast swelling or lumpiness
- Usually affects both breasts, particularly the upper, outer portions and can radiate to the underarm
- Intensifies during the two weeks leading up to the start of your period, then eases up afterward
- Usually affects premenopausal women in their 20s and 30s and perimenopausal women in their 40s

Non-Cyclic breast pain:
- Unrelated to the menstrual cycle
- Described as tight, burning or sore
- Constant or intermittent
- Usually affects one breast, in a localized area, but may spread more diffusely across the breast
- Usually affects postmenopausal women in their 40s and 50s

When to see a doctor for breast pain:

A patient should make an appointment with the doctor if breast pain that persists daily for more than a couple of weeks, if breast pain seems to be getting worse over time or if breast pain interferes with daily activities.

Breast reconstruction\textsuperscript{15}: is a surgical procedure that restores shape to a breast after mastectomy — surgery that removes the breast to treat or prevent breast cancer. This type of breast reconstruction involves taking a section of tissue from one area of the body and relocating it to the chest to create a new breast mound. Breast reconstruction with flap surgery is a complex procedure performed by a plastic surgeon. Often breast reconstruction using the body's own tissue can be accomplished at the time of the mastectomy. In most cases, a patient will need a second operation to achieve a correctly positioned, natural-appearing breast or to perform nipple reconstruction.

\textsuperscript{12} http://www.nlm.nih.gov/medlineplus/ency/article/003155.htm
\textsuperscript{14} http://www.mayoclinic.com/health/breast-pain/DS00760
\textsuperscript{15} http://www.mayoclinic.com/health/breast-reconstruction/MY00173
Breast Ultrasound\(^\text{16}\): Is a procedure that may be used to determine whether a lump is a cyst (sac containing fluid) or a solid mass which could be cancer. If it is found to be a cyst, fluid is typically withdrawn from it using a needle and syringe (a process called aspiration). If clear fluid is removed and the mass completely disappears, no further treatment or evaluation is needed. Ultrasound can also be used to precisely locate the position of a known tumor in order to guide the doctor during a biopsy or aspiration procedure. Ultrasound helps confirm correct needle placement. Ultrasound testing works by transmitting high-frequency sound waves, inaudible to the human ear, through the breast. The sound waves bounce off surfaces in the breast (tissue, air, fluid) and these "echoes" are recorded and transformed into video or photographic images.

Cervical cancer\(^\text{17}\): Cancer that forms in tissues of the cervix (the organ connecting the uterus and vagina). It is usually a slow-growing cancer that may not have symptoms but can be found with regular Pap tests (a procedure in which cells are scraped from the cervix and looked at under a microscope). Cervical cancer is almost always caused by human papillomavirus (HPV) infection.

Chemotherapy\(^\text{18}\): Chemotherapy drugs kill or disable cancer cells. Chemotherapy is a treatment option for most types of breast cancer. Its use in a given person is based on the tumor stage and certain tumor characteristics. The decision to use chemotherapy is also affected by a person’s age, overall health and personal preferences. For those with early breast cancer, chemotherapy is usually given after breast surgery but before radiation treatments. This is called adjuvant therapy and helps to lower the risk of recurrence by getting rid of cancer that might still be present in the body.

Clinical Breast Exam\(^\text{19}\): Clinical breast exams are physical exams done by physicians, nurse practitioners or other trained medical staff. They involve looking at and feeling the breasts and underarm for any changes or abnormalities. The breasts should be checked while the patients are sitting up and while lying down. Clinical breast exams are a part of breast cancer screening and should be thought of as a complement to mammography.

Colonoscopy\(^\text{20}\): In this test, the rectum and entire colon are examined using a lighted instrument called a colonoscope. During colonoscopy, precancerous and cancerous growths throughout the colon can be found and either removed or biopsied, including growths in the upper part of the colon, where they would be missed by sigmoidoscopy. However, it is not yet known for certain whether colonoscopy can help reduce the number of deaths from colorectal cancer. A thorough cleansing of the colon is necessary before this test, and most patients receive some form of sedation.

Colposcopy\(^\text{21}\): A procedure for follow-up testing for some cell changes found in a PAP test, in which an instrument much like a microscope (called a colposcope) is used to examine the vagina and the cervix. During a colposcopy, the doctor inserts a speculum to widen the vagina and may apply a dilute vinegar solution to the cervix, which causes abnormal areas to turn white. The doctor then uses the colposcope (which remains outside the body) to observe the cervix. If colposcopy finds abnormal tissue, the doctor may perform endocervical curettage or a biopsy. A biopsy is the removal of cells or tissues from the abnormal area for examination under a microscope. Endocervical curettage is a type of biopsy that involves scraping cells from inside the endocervical canal with a small spoon-shaped tool called a curette. If testing shows abnormal cells that have a high chance of becoming cancer, further treatment is needed. Without treatment, these cells may turn into cancer. Treatment options include the following:

- LEEP (loop electrosurgical excision procedure) uses an electrical current that is passed through a thin wire loop to act as a knife to remove tissue.
- Cryotherapy destroys abnormal tissue by freezing it.
- Laser therapy uses a narrow beam of intense light to destroy or remove abnormal cells.
- Conization removes a cone-shaped piece of tissue using a knife, a laser, or the LEEP technique.

\(^{16}\) http://www.webmd.com/breast-cancer/guide/breast-ultrasound
\(^{17}\) http://www.cancer.gov/cancertopics/types/cervical
\(^{18}\) http://ww5.komen.org/BreastCancer/Chemotherapy.html
\(^{19}\) http://ww5.komen.org/BreastCancer/ClinicalBreastExam.html
\(^{21}\) http://www.cancer.gov/cancertopics/factsheet/detection/Pap-test
Consent: The approval for healthcare decisions. The patient also must give consent for medical/clinic staff to speak with a family member or friend. The patient can define the amount of information that can be shared with another.

Cultural Competence: requires organizations to have a defined set of values and principles and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally. They should:
- Value diversity;
- Conduct self-assessment;
- Manage the dynamics of difference;
- Acquire and institutionalize cultural knowledge and Adapt to diversity and the cultural contexts of the communities they serve

Digital rectal exam (DRE): In this test, a health care provider inserts a lubricated, gloved finger into the rectum to feel for abnormal areas. DRE allows examination of only the lower part of the rectum. It is often performed as part of a routine physical examination.

Double contrast barium enema (DCBE): In this test, a series of x-rays of the entire colon and rectum are taken after the patient is given an enema with a barium solution and air is introduced into the colon. The barium and air help to outline the colon and rectum on the x-rays. Research shows that DCBE may miss small polyps. It detects about 30 to 50 percent of the cancers that can be found with standard colonoscopy.

Fecal occult blood test (FOBT): This test checks for hidden blood in fecal material (stool). Currently, two types of FOBT are available. One type, called guaiac FOBT, uses the chemical guaiac to detect heme in stool. Heme is the iron-containing component of the blood protein hemoglobin. The other type of FOBT, called immunological FOBT, uses antibodies to detect human hemoglobin protein in stool. Studies have shown that FOBT, when performed every 1 to 2 years in people ages 50 to 80, can help reduce the number of deaths due to colorectal cancer by 15 to 33 percent.

Fibroadenomas: are noncancerous lumps that feel rubbery and are easily moveable within the breast tissue. Like fibrocystic changes, they occur most often during the reproductive years. Usually, they are not tender and, except in rare cases, do not become cancerous later. A doctor may feel fairly certain from an exam that a particular lump is a fibroadenoma. The only way to be sure, however, is to remove or biopsy it.

Fibrocystic changes: can occur in either or both breasts. These changes are common in women (especially during the reproductive years), and are considered a normal variation of breast tissue. Having fibrocystic breasts does not increase your risk for breast cancer. It does, however, make it more difficult to interpret lumps that you or your doctor find on exam. Many women feel tenderness in addition to the lumps and bumps associated with fibrocystic breasts.

Glandular cell abnormalities:
1. AGC—atyypical glandular cells. The glandular cells do not appear normal, but doctors are uncertain about what the cell changes mean.
2. AIS—endocervical adenocarcinoma in situ. Precancerous cells are found in the glandular tissue

Health Insurance Portability and Accountability Act of 1996 (HIPAA): The HIPAA Privacy Rule establishes national standards to protect individuals’ medical records and other personal health information and applies to health plans, health care clearinghouses, and those health care providers that conduct certain health care transactions electronically. The Rule requires appropriate safeguards to protect the privacy of personal health information, and sets limits and conditions on the uses and disclosures that may be made of such information without patient authorization. The Rule also gives patient’s rights over their health information, including rights to examine and obtain a copy of their health records, and to request corrections.

22 (adapted from Cross et al., 1989 http://www11.georgetown.edu/research/gucchd/nccc/framework)
28 http://www.cancer.gov/cancertopics/factsheet/detection/Pap-test
29 http://www.hhs.gov/ocr/privacy/hipaa/administrative/privacyrule/index.html
**Health Literacy:** Health literacy is defined in *Health People 2010* as: "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions".

**Hormone therapy**[^30]: Treatment that adds, blocks, or removes hormones. For certain conditions (such as diabetes or menopause), hormones are given to adjust low hormone levels. To slow or stop the growth of certain cancers (such as prostate and breast cancer), synthetic hormones or other drugs may be given to block the body’s natural hormones. Sometimes surgery is needed to remove the gland that makes a certain hormone. Also called endocrine therapy, hormonal therapy, and hormone treatment.

**Lumpectomy**[^31]: (also known as breast conserving surgery or wide excision) is a common treatment for breast cancer. The procedure removes only part of the breast (the tumor and some of the normal tissue around it). This leaves the breast looking as close as possible to how it looked before surgery. Usually, the shape of the breast is preserved, as is the nipple area. Radiation therapy is given after the surgery to get rid of any cancer cells that may remain. This lowers the chances of the cancer coming back.

**Mastectomy**[^32]:
- Simple Mastectomy: In a total or simple mastectomy, the surgeon removes the entire breast but no other tissue or nodes. This type of mastectomy is used to treat ductal carcinoma in situ, Paget's disease with underlying non-invasive cancer and, in some cases, recurrent breast cancer. It is also used for women at higher risk who undergo mastectomy to try to prevent breast cancer.
- Modified Radical Mastectomy: In a modified radical mastectomy, the surgeon removes the breast, the lining of the chest muscles and some of the lymph nodes in the armpit (called axillary dissection). In many cases, axillary dissection can be replaced by sentinel node biopsy. This type of mastectomy is used to treat invasive cancers, including early breast cancer, locally advanced breast cancer, inflammatory breast cancer and Paget's disease with underlying invasive breast cancer.

**Mammogram**[^33]:
- Screening Mammogram: Mammography is a screening tool that uses X-rays to create an image of the breast. These images, called mammograms (MAM-grams), are used to find signs of breast cancer such as tumors, small clusters of calcium (microcalcifications) and abnormal changes in the skin. The X-ray images of the breast are captured on film (standard mammography) or stored directly onto a computer (digital mammography). Film and digital mammography are similar in their ability to detect cancer. However, digital images can be viewed in different ways on a computer. They can be lightened or darkened, and certain sections can be enlarged and examined more closely. The ability to control digital images on a computer makes digital mammography more accurate for some women.
- Diagnostic mammogram: Diagnostic mammograms take longer than screening mammograms because they involve more x-rays in order to obtain views of the breast from several angles. The technician may magnify a suspicious area to produce a detailed picture that can help the doctor make an accurate diagnosis.

**Medical Home**[^34]: The Patient Centered Medical Home is a health care setting that facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient’s family. Care is facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.

[^31]: http://ww5.komen.org/BreastCancer/Lumpectomy.html
[^32]: http://ww5.komen.org/BreastCancer/Mastectomy.html
[^33]: http://ww5.komen.org/BreastCancer/Mammography.html
[^34]: http://www.ncqa.org/tabid/631/default.aspx
“Minimal Clinical Elements for Breast Cancer Detection and Diagnosis” developed by the Medical Advisory Committee for the Breast and Cervical Cancer Program (BCCP) to serve as guidelines for the screening and management of women receiving breast cancer screening through the BCCP and diagnostic services through the BCCP Expanded.

✓ **Goal**: The goal of the Minimal Clinical Elements for Breast Cancer Detection and Diagnosis is to provide clients of the Maryland Breast and Cervical Cancer Program (BCCP) with optimal, up-to-date screening for breast cancer and management of findings.

✓ **Objective**: To provide clinical guidelines for breast cancer screening and diagnostic testing including interpretation and management of results of clinical breast examination, mammography, and diagnostic testing.

**Pap test**[^36]: (sometimes called a Pap smear or cervical cytology) is a way to examine cells collected from the cervix (the lower, narrow end of the uterus). The main purpose of the Pap test is to detect cancer or abnormal cells that may lead to cancer. It can also find noncancerous conditions, such as infection and inflammation.

**Pelvic Exam**[^37]: In a pelvic exam, the uterus, vagina, ovaries, fallopian tubes, bladder, and rectum are felt to find any abnormality in their shape or size. During a pelvic exam, an instrument called a speculum is used to widen the vagina so that the upper portion of the vagina and the cervix can be seen.

**Paget's (PAJ-uts) Disease**: of the breast is a rare form of breast cancer, accounting for less than 5 percent of all breast cancers. Paget's disease of the breast starts in the breast ducts and extends to the skin of the nipple and to the dark circle of skin (areola) around the nipple. Paget's disease of the breast isn't related to Paget's disease of the bone, a metabolic bone disease.

Symptoms include:

✓ Flaky or scaly skin on your nipple; Redness; Itching; Crusty, oozing or hardened skin resembling eczema, on the nipple; areola or both; A burning sensation; Straw-colored or bloody nipple discharge; A flattened or inverted nipple ; Affected areas beyond the nipple and areola; A distinct lump underneath the nipple and areola: Skin and nipple changes usually in one breast only; Fluctuating skin changes early on, making it appear as if your skin is healing on its own

✓ On average, a woman may experience signs and symptoms for six to eight months before a diagnosis is made.

**Protected Health Information (PHI)**: The Privacy Rule protects all "individually identifiable health information" held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral. The Privacy Rule calls this information "protected health information (PHI)." "Individually identifiable health information" is information, including demographic data, that relates to:

✓ the individual’s past, present or future physical or mental health or condition,

✓ the provision of health care to the individual, or

✓ the past, present, or future payment for the provision of health care to the individual, and that identifies the individual or for which there is a reasonable basis to believe can be used to identify the individual. Individually identifiable health information includes many common identifiers (e.g., name, address, birth date, Social Security Number).

**Prostate-specific antigen (PSA)** is a tumor marker currently used for early detection of prostate cancer.


[^36]: http://www.cancer.gov/cancertopics/factsheet/detection/Pap-test

[^37]: http://www.cancer.gov/cancertopics/factsheet/detection/Pap-test
Radiation Therapy\textsuperscript{38}: Radiation therapy (also known as radiotherapy) uses targeted, high-energy X-rays to kill cancer cells. For women with early stage breast cancer, radiation therapy is used after surgery to kill cancer that might be left in or around the breast or chest. This is most important with lumpectomy (also called breast conserving surgery), since much of the breast tissue is left intact.

Sentinel Node Biopsy\textsuperscript{39}: SLN biopsy is a procedure in which the sentinel lymph node is removed and examined under a microscope to determine whether cancer cells are present. SLN biopsy is based on the idea that cancer cells spread (metastasize) in an orderly way from the primary tumor to the sentinel lymph node(s), then to other nearby lymph nodes.

A negative SLN biopsy result suggests that cancer has not spread to the lymph nodes. A positive result indicates that cancer is present in the SLN and may be present in other lymph nodes in the same area (regional lymph nodes). This information may help the doctor determine the stage of cancer (extent of the disease within the body) and develop an appropriate treatment plan.

Sigmoidoscopy\textsuperscript{40}: In this test, the rectum and lower colon are examined using a lighted instrument called a sigmoidoscope. During sigmoidoscopy, precancerous and cancerous growths in the rectum and lower colon can be found and either removed or biopsied. Studies suggest that regular screening with sigmoidoscopy after age 50 can help reduce the number of deaths from colorectal cancer. A thorough cleansing of the lower colon is necessary for this test.

Squamous cell abnormalities\textsuperscript{41}:

- **ASC**—atypical squamous cells. This is the most common abnormal finding in Pap tests. The Bethesda System divides this category into two groups:
  - ASC-US—atypical squamous cells of undetermined significance. The squamous cells do not appear completely normal, but doctors are uncertain about what the cell changes mean. Sometimes the changes are related to HPV infection, but they can also be caused by other factors. For women who have ASC-US, a sample of cells may be tested for the presence of high-risk HPV types. If high-risk HPV is present, colposcopy will usually be performed. On the other hand, a negative HPV test can provide reassurance that cancer or a precancerous condition is not present.
  - ASC-H—atypical squamous cells, cannot exclude a high-grade squamous intraepithelial lesion. The cells do not appear normal, but doctors are uncertain about what the cell changes mean. ASC-H lesions may be at higher risk of being precancerous compared with ASC-US lesions.

- **LSIL**—low-grade squamous intraepithelial lesion. Low-grade means that there are early changes in the size and shape of cells. Intraepithelial refers to the layer of cells that forms the surface of the cervix. LSILs are considered mild abnormalities caused by HPV infection. LSILs are sometimes referred to as mild dysplasia (dysplasia means abnormal cells that are not cancer but have the potential to become cancer). They may also be referred to as cervical intraepithelial neoplasia (CIN-1). (Neoplasia means an abnormal growth of cells, and the number describes how much of the thickness of the lining of the cervix contains abnormal cells—only the top layer, in this case.)

- **HSIL**—high-grade squamous intraepithelial lesion. High-grade means that there are more evident changes in the size and shape of the abnormal (precancerous) cells and that the cells look very different from normal cells. HSILs are more severe abnormalities that have a higher likelihood of progressing to cancer. HSILs include lesions with moderate or severe dysplasia or carcinoma in situ. (In carcinoma in situ, abnormal cells are present only on the surface of the cervix. Although they are not cancer, these abnormal cells may become cancer and spread into nearby healthy tissue.) HSIL lesions are sometimes referred to as CIN-2, CIN-3, or CIN-2/3, indicating that the abnormal cells occupy most of the layers of the lining of the cervix.

- **Squamous cell carcinoma**. Cervical cancer is when abnormal cervical squamous cells invade deeper into the cervix or to other tissues or organs. In a well-screened population, such as that in the United States, a finding of cancer on a Pap test is extremely rare.

\textsuperscript{38} http://ww5.komen.org/BreastCancer/Radiation.html
\textsuperscript{39} http://www.cancer.gov/cancertopics/factsheet/therapy/sentinel-node-biopsy
\textsuperscript{40} http://www.cancer.gov/cancertopics/factsheet/Detection/colorectal-screening
\textsuperscript{41} http://www.cancer.gov/cancertopics/factsheet/detection/Pap-test
**Virtual colonoscopy**\(^{42}\): (also called computerized tomographic colonography)—In this test, special x-ray equipment is used to produce pictures of the colon and rectum. A computer then assembles these pictures into detailed images that can show polyps and other abnormalities. Because it is less invasive than standard colonoscopy and sedation is not needed, virtual colonoscopy may cause less discomfort and take less time to perform. As with standard colonoscopy, a thorough cleansing of the colon is necessary before this test. Whether virtual colonoscopy can reduce the number of deaths from colorectal cancer is not yet known.

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Appendix 1

H.R. 1812: Patient Navigator Outreach and Chronic Disease Prevention Act of 2005

Congressional Research Service Summary

The following summary was written by the Congressional Research Service, a well-respected nonpartisan arm of the Library of Congress.

(This measure has not been amended since it was passed by the House on June 13, 2005. The summary of that version is repeated here.)

Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 –

Section 2 -
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. 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.

Sets forth reporting requirements.

Authorizes appropriations.43

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Appendix 2

Cancer Screening Guidelines

Numerous medical organizations have developed cancer screening guidelines. Faced with the broad, and sometimes conflicting, range of recommendations for cancer screening, family physicians must determine the most reasonable and up-to-date method of screening. Major medical organizations have generally achieved consensus on screening guidelines for breast, cervical and colorectal cancer. For breast cancer screening in women ages 50 to 70, clinical breast examination and mammography are generally recommended every one or two years, depending on the medical organization. For cervical cancer screening, most organizations recommend a Papanicolaou test and pelvic examination at least every three years in patients between 20 and 65 years of age. Annual fecal occult blood testing along with flexible sigmoidoscopy at five-year to 10-year intervals is the standard recommendation for colorectal cancer screening in patients older than 50 years. Screening for prostate cancer remains a matter of debate.

Some organizations recommend digital rectal examination and a serum prostate-specific antigen test for men older than 50 years, while others do not. In the absence of compelling evidence to indicate a high risk of endometrial cancer, lung cancer, oral cancer and ovarian cancer, almost no medical organizations have developed cancer screening guidelines for these types of cancer. Several studies show that primary care physicians do not always comply with cancer screening guidelines. One reason is that recommendations for cancer detection and screening are often fragmented in the sense that they are developed by various medical organizations, which may make decision-making more difficult as far as which recommendations to follow.

Summary of Cancer Screening Recommendations for Low-Risk Patients The recommendations listed below are a sample of recommendations that are offered by various organizations. A clinic should establish the specific guideline they will follow

**Breast Cancer**

<table>
<thead>
<tr>
<th>Medical organization</th>
<th>Screening recommendations</th>
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<tbody>
<tr>
<td>American Academy of Family Physicians</td>
<td>The AAFP recommends that the decision to conduct screening mammography before age 50 should be individualized and take into account patient context including her risks as well as her values regarding specific benefits and harms. (January 2010). The AAFP recommends biennial (every two years) screening mammography for women between ages 50 and 74. (January 2010)</td>
</tr>
<tr>
<td>American College of Obstetricians and Gynecologists</td>
<td>Based on the incidence of breast cancer, the sojourn time for breast cancer growth, and the potential reduction in breast cancer mortality, the College recommends that women aged 40 years and older be offered screening mammography annually. (8/2100)</td>
</tr>
<tr>
<td>American Cancer Society</td>
<td>Yearly mammograms are recommended, starting at age 40 and continuing for as long as a woman is in good health</td>
</tr>
<tr>
<td>U.S. Preventive Services Task Force</td>
<td>The USPSTF recommends biennial screening mammography for women aged 50 to 74 years2/209</td>
</tr>
</tbody>
</table>

Cancer Screening Guidelines
ROGER ZOOROB, M.D., M.P.H., RUSSELL ANDERSON, M.D., CHARLES CEFALU, M.D., M.S., and MOHAMAD SIDANI, M.D., M.S., Louisiana State University School of Medicine, Department of Family Medicine, New Orleans, Louisiana, Am Fam Physician. 2001 Mar 15;63(6):1101-1113.
### Clinical Breast Exam

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<tr>
<td>American Academy of Family Physicians</td>
<td>The AAFP concludes that the current evidence is insufficient to assess the benefits and harms of clinical breast examination (CBE) for women aged 40 years and older. (January 2010).</td>
</tr>
<tr>
<td>American College of Obstetricians and Gynecologists</td>
<td>Clinical breast examination should be performed annually for women aged 40 years and older. For women aged 20–39 years, clinical breast examinations are recommended every 1–3 year</td>
</tr>
<tr>
<td>American Cancer Society</td>
<td>Clinical breast exam (CBE) about every 3 years for women in their 20s and 30s and every year for women 40 and over.</td>
</tr>
<tr>
<td>U.S. Preventive Services Task Force</td>
<td>The USPSTF concludes that the current evidence is insufficient to assess the additional benefits and harms of clinical breast examination (CBE) beyond screening mammography in women 40 years or older. (12/2009)</td>
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### Cervical Cancer

#### Cervical Screening

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<tr>
<td>American Academy of Family Physicians</td>
<td>• The AAFP recommends screening for cervical cancer in women age 21 to 65 years with cytology (Pap smear) every 3 years or, for women age 30 to 65 years who want to lengthen the screening interval, screening with a combination of cytology and human papillomavirus (HPV) testing every 5 years. (2012)&lt;br&gt;• The AAFP recommends against screening for cervical cancer in women younger than age 21 years. (2012)&lt;br&gt;• The AAFP recommends against screening for cervical cancer in women who have had a hysterectomy with removal of the cervix and who do not have a history of a high-grade precancerous lesion (cervical intraepithelial neoplasia [CIN] grade 2 or 3) or cervical cancer. (2012)</td>
</tr>
<tr>
<td>American College of Obstetricians and Gynecologists</td>
<td>• The American Congress of Obstetricians and Gynecologists recommends that all women should have their first Pap test at age 21.&lt;br&gt;• Women between the ages of 21 and 29 need a Pap test every two years, using either the standard method or liquid based cytology.&lt;br&gt;• Low-risk women ages 30 to 64 who have had three consecutive normal Pap tests can be screened every three years. Another option includes combining aPap test with an HPV DNA test (every three years if both are normal.&lt;br&gt;• Low-risk women ages 65 and older, who have had three or more normal Pap tests within the last 10 years, can discontinue Pap testing unless they have risk factors for sexually transmitted diseases.&lt;br&gt;• Slightly abnormal Pap results may be followed up by an HPV test, a repeat Pap test, or colposcopy.</td>
</tr>
<tr>
<td>U.S. Preventive Services Task Force</td>
<td>• The USPSTF recommends screening for cervical cancer in women ages 21 to 65 years with cytology (Pap smear) every 3 years or, for women ages 30 to 65 years who want to lengthen the screening interval, screening with a combination of cytology and human papillomavirus (HPV) testing every 5 years. (3/2012)</td>
</tr>
</tbody>
</table>
### Colorectal Cancer Screening

<table>
<thead>
<tr>
<th>Medical organization</th>
<th>Screening recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Academy of Family Physicians</td>
<td>The AAFP recommends screening for colorectal cancer using fecal occult blood testing, sigmoidoscopy, or colonoscopy, in adults, beginning at age 50 years and continuing until age 75 years. The risk and benefits of these screening methods vary. (2008)</td>
</tr>
</tbody>
</table>
| American College of Obstetricians and Gynecologists       | After age 50, annual FOBT (DRE* should accompany pelvic examination); sigmoidoscopy every 3 to 5 years  
*DRE = digital rectal examination                                                                                                           |
| American Cancer Society /AGA                              | Flexible sigmoidoscopy every 5 years or Colonoscopy every 10 years or Double-contrast barium enema every 5 years  Yearly fecal occult blood test (gFOBT) or yearly fecal immunochemical test (FIT) every year.                                                                                                                      |
| U.S. Preventive Services Task Force                       | The USPSTF recommends screening for colorectal cancer (CRC) using fecal occult blood testing, sigmoidoscopy, or colonoscopy, in adults, beginning at age 50 years and continuing until age 75 years. (10/2008)                                                                                                             |

### Prostate Cancer Screening

<table>
<thead>
<tr>
<th>Medical organization</th>
<th>Screening recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Academy of Family Physicians</td>
<td>The AAFP recommends against prostate-specific antigen (PSA)-based screening for prostate cancer. (2012)</td>
</tr>
<tr>
<td>American Cancer Society</td>
<td>Starting at age 50, men should talk to a doctor about the pros and cons of testing so they can decide if testing is the right choice for them. If they are African American or have a father or brother who had prostate cancer before age 65, men should have this talk with a doctor starting at age 45. If men decide to be tested, they should have the PSA blood test with or without a rectal exam. How often they are tested will depend on their PSA level.</td>
</tr>
<tr>
<td>U.S. Preventive Services Task Force</td>
<td>The USPSTF recommends against PSA-based screening for prostate cancer.</td>
</tr>
</tbody>
</table>

### Skin Cancer Screening

<table>
<thead>
<tr>
<th>Medical organization</th>
<th>Screening recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Academy of Family Physicians</td>
<td>The AAFP concludes that the current evidence is currently insufficient to assess the balance of benefits and harms of using a whole-body skin examination by a primary care clinician or patient skin self examination for the early detection of cutaneous melanoma, basal cell cancer, or squamous cell skin cancer in the adult general population (2009)</td>
</tr>
<tr>
<td>American Cancer Society</td>
<td>For people aged 20 or older having periodic health exams, a cancer-related check-up should include health counseling and, depending on a person’s age and gender, exams for cancers of the skin</td>
</tr>
<tr>
<td>U.S. Preventive Services Task Force</td>
<td>The USPSTF recommends against PSA-based screening for prostate cancer.</td>
</tr>
</tbody>
</table>

### Testicular Cancer Screening

<table>
<thead>
<tr>
<th>Medical organization</th>
<th>Screening recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Academy of Family Physicians</td>
<td>The AAFP recommends against screening for testicular cancer in asymptomatic adolescent or adult males (2011). For people aged 20 or older having periodic health exams, a cancer-related check-up should include health counseling and, depending on a person’s age and gender, exams for cancer of the testes.</td>
</tr>
<tr>
<td>U.S. Preventive Services Task Force</td>
<td>The U.S. Preventive Services Task Force (USPSTF) recommends against screening for testicular cancer in adolescent or adult males. (4/2011)</td>
</tr>
</tbody>
</table>
Appendix 3

ACOG Cancer Screening (Follow-up) Guidelines

| First Pap | Women Age 21 (regardless of age of first intercourse) |
| Last Pap | Women age 65-70 if 3 or more consecutive Paps in past 10 years and not high risk for cervical cancer |
| Hysterectomy | No screening if hysterectomy done for benign disease and no history of CIN (cervical intraepithelial neoplasia) II or III |

**Exceptions**
- History of CIN II or CIN III or cancer
- Immunocompromised (ie, HIV, transplant patients)
- DES (diethylstilbestrol) in utero

**Negative**
- Age 21 to 29 screen every 2 years.
- Age 30 and older repeat every 3 years if
  - Negative cytology X 3 documented consecutive
  - NIELM (Negative for intraepithelial lesion or malignancy) and negative HR HPV test in 1 year
  - No history of high grade lesions

**Unsatisfactory**
- Repeat Pap
- AGC
  - Atypical Glandular Cells
    - Endometrial Biopsy (EMB)
    - Endometrial Curretage (ECC)
    - If no endometrial pathology → Colposcopy

**ASC-US**
- Atypical Squamous Cells – Undetermined significance
  - Reflex HPV (Human Papillomanivirus) testing
  - Positive → Colposcopy
  - Negative → Repeat Pap in 12 months

**ASC-H**
- Atypical Squamous Cells - No exclude high grade
  - Colposcopy

**LSIL**
- Low Grade Squamous Intraepithelial Lesion (encompasses CIN I)
  - Colposcopy

**HSIL**
- High Grade Squamous Intraepithelial Lesion (encompasses CIN II and III)
  - Colposcopy

**Squamous Cell Carcinoma**
- Colposcopy

**Adenocarcinoma in situ**
- Colposcopy, EMB, ECC
- Diagnostic Excisional Procedure/Total Hysterectomy

---

45 http://www.acog.org/ACOG_Districts/dist1jf/teachingmodulecervicalcancer.ppt#269,10,Management of Abnormal Paps
Appendix 4
Patient Navigation Intake

<table>
<thead>
<tr>
<th>Patient Name:</th>
<th>DOB</th>
<th>MRN</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What does patient prefer to be called?</strong></td>
<td><strong>Address:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Phone #:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(H) <strong><strong><strong>-</strong>__-</strong></strong>  (C) <strong><strong><strong>-</strong>__-</strong></strong>  (W) <strong><strong><strong>-</strong>__-</strong></strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Best time to contact:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ M  ☐ T  ☐ W  ☐ Th  ☐ F</td>
<td>☐ Morning  ☐ Afternoon  ☐ Evening</td>
<td></td>
</tr>
<tr>
<td><strong>Can a message be left on the phone(s)?</strong></td>
<td>☐ Yes  ☐ No</td>
<td></td>
</tr>
<tr>
<td><strong>Country of origin:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Years in this country:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Primary language?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Can patient speak English?</strong></td>
<td>☐ Yes  ☐ No</td>
<td></td>
</tr>
<tr>
<td><strong>Can patient read English?</strong></td>
<td>☐ Yes  ☐ No</td>
<td></td>
</tr>
<tr>
<td><strong>Translator needed?</strong></td>
<td>☐ Yes  ☐ No</td>
<td></td>
</tr>
<tr>
<td><strong>Emergency Contact Name:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Days to contact:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Does patient work/attend school?</strong></td>
<td>☐ Yes  ☐ No</td>
<td></td>
</tr>
<tr>
<td><strong>Usual work days/hours:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Does the patient subscribe to a religion?</strong></td>
<td>☐ No  ☐ Yes:</td>
<td></td>
</tr>
<tr>
<td><strong>If yes, importance in health matters?</strong></td>
<td>☐ Low  ☐ Medium  ☐ High</td>
<td></td>
</tr>
</tbody>
</table>

**Health Insurance**
- ☐ Medicaid
- ☐ Medicare
- ☐ Private/Commercial
- ☐ No health insurance

**Referred by:**

**Primary Provider:**

**Diagnosis:**

**What has the patient been told about diagnosis?**

**Acute Symptoms:**

**Co-morbidities:**
- ☐ None
- ☐ Diabetes
- ☐ Hypertension
- ☐ CAD
- ☐ CHF
- ☐ COPD
- ☐ Persistent Pain
- ☐ Obesity
- ☐ Depression
- ☐ Substance abuse
- ☐ Other:

**Medications:**

**Upcoming appointments:**
- **Reason:**
- **Practitioner:**
- **Date:**
- **Time:**

**Strengths:** (Check all that apply)
- ☐ Understands condition and needs
- ☐ Adherent to treatment recommendations
- ☐ Stable home environment
- ☐ Good support systems
- ☐ Financially stable
- ☐ Fluent in English
- ☐ Good communication skills
- ☐ Other:

**Barriers:** (Check all that apply)
- ☐ Inadequate or lack of health care insurance
- ☐ Personal financial difficulties
- ☐ Communication barriers/Language translation
- ☐ Inability to read or write
- ☐ Poor health literacy
- ☐ Cultural concerns
- ☐ Citizenship problems/undocumented status
- ☐ Disabilities (physical)
- ☐ Disabilities (cognitive)
- ☐ Reactions of family/peers
- ☐ Child/elder care concerns
- ☐ Transportation
- ☐ Lack of knowledge about diagnosis and treatment
- ☐ Other:
Appendix 5
Patient Navigation---- Cancer Treatment Plan and Summary

<table>
<thead>
<tr>
<th>Demographics</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Name:</td>
<td>DOB/Age:</td>
<td>MRN:</td>
</tr>
<tr>
<td>What does the patient prefer to be called?</td>
<td>Address:</td>
<td></td>
</tr>
<tr>
<td>Phone #:</td>
<td>Best time to contact:</td>
<td></td>
</tr>
<tr>
<td>(H) --- - - - - (C) --- - - - - (W) --- - - -</td>
<td>□ M  □ T  □ W  □ Th  □ F</td>
<td></td>
</tr>
<tr>
<td>Can a message be left on the phone(s)?</td>
<td>□ Yes  □ No</td>
<td></td>
</tr>
<tr>
<td>Country of origin:</td>
<td>Emergency/Support Contact Name:</td>
<td></td>
</tr>
<tr>
<td>Years in this country:</td>
<td>Relationship:</td>
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</tr>
<tr>
<td>Primary language:</td>
<td>Phone</td>
<td></td>
</tr>
<tr>
<td>Can patient speak English?</td>
<td>□ Yes  □ No</td>
<td></td>
</tr>
<tr>
<td>Can patient read English?</td>
<td>□ Yes  □ No</td>
<td></td>
</tr>
<tr>
<td>Translator needed:</td>
<td>□ Yes  □ No</td>
<td></td>
</tr>
<tr>
<td>Health Insurance</td>
<td>Financial Assistance Program</td>
<td></td>
</tr>
<tr>
<td>□ Medicaid  □ Medicare  □ Private/Commercial  □ No health insurance</td>
<td>Program:</td>
<td></td>
</tr>
<tr>
<td>Financial</td>
<td>Approval #:</td>
<td></td>
</tr>
<tr>
<td>Financial Assistance Program</td>
<td>Start Date:  End Date:</td>
<td></td>
</tr>
<tr>
<td>Clinical Information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer Type/Location:</td>
<td>Diagnosis Date</td>
<td>Is cancer diagnosis</td>
</tr>
<tr>
<td>____________________________</td>
<td>(<em>/__/</em>___)</td>
<td>□ New  □ Recurrent (date <em>/__/</em>___)</td>
</tr>
<tr>
<td>Staging</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Date</td>
<td>Findings</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T stage: □ T1  □ T2  □ T3  □ T4  □ Not applicable</td>
<td>N stage: □ N0  □ N1  □ N2  □ N3  □ Not applicable</td>
<td></td>
</tr>
<tr>
<td>M stage: □ M0  □ M1  □ Not applicable</td>
<td>Tumor markers:</td>
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</tr>
<tr>
<td>Stage: □ I  □ II  □ III  □ IV  □ Recurrence</td>
<td>Alternative staging system:</td>
<td></td>
</tr>
<tr>
<td>Location(s) of metastasis or recurrence (if applicable):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-morbidities:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ None  □ Diabetes  □ Hypertension  □ Heart Disease  □ Anemia  □ COPD  □ Asthma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Kidney Disease  □ Liver Disease  □ Depression  □ Substance Abuse  □ Other:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current symptoms:</td>
<td>Date of first symptoms:</td>
<td></td>
</tr>
<tr>
<td>Family history/Predisposing conditions:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Patient Questionnaire (common concerns of cancer patients)

<table>
<thead>
<tr>
<th>Concern</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Muscle aches</td>
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</tr>
<tr>
<td>Pain</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Weakness/Decreased mobility</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tingling/numbness in hands or feet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep difficulty</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory decline</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hot flashes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vaginal dryness</td>
<td></td>
<td></td>
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<tr>
<td>Sexuality Change in menstrual patterns changes or concerns</td>
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</tr>
<tr>
<td>Weight changes</td>
<td></td>
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<tr>
<td>Inability/difficulty working</td>
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<tr>
<td>Difficulty with family/other relationships</td>
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<tr>
<td>Other (specify)</td>
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</tr>
<tr>
<td>Other (specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
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<td>Sleep difficulty</td>
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<tr>
<td>Memory decline</td>
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<tr>
<td>Hot flashes</td>
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<tr>
<td>Other (specify)</td>
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<tr>
<td>Other (specify)</td>
<td></td>
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</tbody>
</table>

### Treatment Plan

**Recommended treatment:**
- chemotherapy
- radiation therapy
- surgery
- hormonal therapy
- other

**Clinical trial candidate?**
- yes
- no

### Treatment Team

<table>
<thead>
<tr>
<th>Practitioner</th>
<th>Name</th>
<th>Contact Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Oncologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation Oncologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgeon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral Health Practitioner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic Counselor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plastic Surgeon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Treatment

**Surgery:**
- Site: [ ]
- Date: [ ]
- Hospital: [ ]
- Report received? [ ] Yes [ ] No

**Chemotherapy:**
- Start date: [ ]
- End date: [ ]
- Reason for stopping treatment:
  - [ ] Completion
  - [ ] Toxicity
  - [ ] Progression
  - [ ] Other [ ]
- Response to treatment:
  - [ ] Complete
  - [ ] Partial
  - [ ] No response
  - [ ] Progression
  - [ ] Non-measurable
- Report received? [ ] Yes [ ] No

**Radiation therapy:**
- Region treated: [ ]
- Start Date: [ ]
- Completed Date: [ ]
- Radiologist: [ ]
- Phone #: [ ]
- Report received? [ ] Yes [ ] No

**Additional therapies:**
- Type: [ ]
- Start Date: [ ]
- Comments: [ ]
- [ ]
- [ ]
- [ ]
- [ ]

**Treatment Notes:**

---

27
# Patient Evaluation

**Strengths:** (Check all that apply)
- ☐ Understands condition and needs
- ☐ Adherent to treatment recommendations
- ☐ Stable home environment
- ☐ Good support systems
- ☐ Financially stable
- ☐ Fluent in English
- ☐ Good communication skills
- ☐ Other: __________________________ 
- ☐ Other: __________________________

**Barriers:** (Check all that apply)
- ☐ Inadequate or lack of health care insurance
- ☐ Personal financial difficulties
- ☐ Communication barriers/Language translation
- ☐ Inability to read or write
- ☐ Poor health literacy
- ☐ Cultural concerns
- ☐ Citizenship problems/undocumented status
- ☐ Disabilities (physical)
- ☐ Disabilities (cognitive)
- ☐ Reactions of family/peers
- ☐ Child/elder care concerns
- ☐ Transportation
- ☐ Lack of knowledge about diagnosis and treatment
- ☐ Other: __________________________ 
- ☐ Other: __________________________

## Needs/Concerns

**Needs or Concerns:**
- ☐ Transportation
- ☐ Support
- ☐ Education
- ☐ Personal Care
- ☐ Financial advice/assistance
- ☐ Legal advice/assistance
- ☐ Prevention and wellness
- ☐ Nutrition
- ☐ Genetic Risk
- ☐ Emotional or mental health
- ☐ Personal relationships
- ☐ Other: __________________________ 
- ☐ Other: __________________________

Comments:

## Referrals

<table>
<thead>
<tr>
<th>Referral</th>
<th>Date</th>
<th>Organization/Facility/Practitioner</th>
<th>Phone#</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Support Group</td>
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</tr>
<tr>
<td>Financial Aid</td>
<td></td>
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<tr>
<td>Legal Aid</td>
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<tr>
<td>Behavioral Health</td>
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</tr>
<tr>
<td>Dietician</td>
<td></td>
<td></td>
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</table>

## Follow-up Care and Survivorship Care

<table>
<thead>
<tr>
<th>Follow-up Care Visits</th>
<th>Frequency</th>
<th>Date</th>
<th>Provider</th>
<th>Comments</th>
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</tbody>
</table>

Special Needs:

Signature: __________________________ Date: __________________________
Appendix 6
Sample Letters

Sample Letter
Unable to Contact Patient (Patient Navigator)

(Clinic/Practice/Facility Letterhead Here)

(Date)

(Patient’s Name and Address)

Dear (Patient’s Name):

We at (Clinic/Practice/Facility) want you to receive excellent healthcare. I have been trying to reach you at the numbers listed in your patient record but have been unable to get in touch with you. Please call me at (phone number) as soon as possible.

I would like to discuss the following with you:

☐ Scheduling an appointment.
☐ Your ___________ results.
☐ Your application for diagnostic and treatment services.
☐ Other: ______________________________________
     ______________________________________

Sincerely,

(Patient Navigator)
(Clinic/Practice/Facility) Letterhead Here)

(Date)

(Patient’s Name and Address)

Dear (Patient’s Name):

We at (Clinic/Practice/Facility) want you to receive excellent healthcare. You recently had (Name of test) performed at (Lab/Radiology Provider). I have been unable to contact you to discuss your results. The results of your recent (Name of test) were:

- Incomplete. I recommend that you repeat the mammogram in the next month. Please contact (Patient Navigator at phone number), to arrange a for repeat testing.

- Abnormal. It is very important that you schedule a follow-up appointment with me as soon as possible to discuss your results.

- Other: ________________________________________________________________

Please call (Patient Navigator at phone number) with any questions or concerns.

Sincerely,

(Provider)
## Appendix 7

### Patient Navigation Tracking

Name/MRN | Navigation | Intervention | Intervention Type | Day | Time | Challenges |
<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Breast</td>
<td>Scheduling appointment</td>
<td>Face to Face</td>
<td>M</td>
<td></td>
<td>Language</td>
</tr>
<tr>
<td></td>
<td>Cervical</td>
<td>State/Charity Application</td>
<td>Phone Call</td>
<td>T</td>
<td></td>
<td>Literacy</td>
</tr>
<tr>
<td></td>
<td>Colorectal</td>
<td>Follow-up</td>
<td>Phone Message</td>
<td>W</td>
<td></td>
<td>Unable to contact</td>
</tr>
<tr>
<td></td>
<td>Diabetes</td>
<td>Education</td>
<td>Written</td>
<td>TH</td>
<td></td>
<td>Non-Adherence</td>
</tr>
<tr>
<td></td>
<td>Chronic Illness</td>
<td>Record Request</td>
<td>Fax</td>
<td>F</td>
<td></td>
<td>Computer problems</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>Data Entry</td>
<td>E-mail</td>
<td>S</td>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>

|          | Breast     | Scheduling appointment | Face to Face | M  |       | Language   |
|          | Cervical   | State/Charity Application | Phone Call | T  |       | Literacy   |
|          | Colorectal | Follow-up | Phone Message | W  |       | Unable to contact |
|          | Diabetes   | Education | Written | TH |       | Non-Adherence |
|          | Chronic Illness | Record Request | Fax | F  |       | Computer problems |
|          | Other      | Data Entry | E-mail | S  |       | Other      |

|          | Breast     | Scheduling appointment | Face to Face | M  |       | Language   |
|          | Cervical   | State/Charity Application | Phone Call | T  |       | Literacy   |
|          | Colorectal | Follow-up | Phone Message | W  |       | Unable to contact |
|          | Diabetes   | Education | Written | TH |       | Non-Adherence |
|          | Chronic Illness | Record Request | Fax | F  |       | Computer problems |
|          | Other      | Data Entry | E-mail | S  |       | Other      |

|          | Breast     | Scheduling appointment | Face to Face | M  |       | Language   |
|          | Cervical   | State/Charity Application | Phone Call | T  |       | Literacy   |
|          | Colorectal | Follow-up | Phone Message | W  |       | Unable to contact |
|          | Diabetes   | Education | Written | TH |       | Non-Adherence |
|          | Chronic Illness | Record Request | Fax | F  |       | Computer problems |
|          | Other      | Data Entry | E-mail | S  |       | Other      |
Appendix 8

Patient Navigation Pre-Assessment Tool

Goals:
1. What is the goal(s) of your navigation program?
   - Improved Health Outcomes
   - Better Patient Experience
   - Improved Quality Measures
   - Accreditation
   - Grant Fulfillment
   - Other: __________________________________________________________

Operations:
1. What kind of patient navigation is being planned for your practice/ facility?

<table>
<thead>
<tr>
<th>Patient Navigation</th>
<th>Specific Diagnostic Group (ie. Breast Cancer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outreach</td>
<td></td>
</tr>
<tr>
<td>Cancer screening</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td></td>
</tr>
<tr>
<td>Chronic Illness</td>
<td></td>
</tr>
<tr>
<td>Complex Medical</td>
<td></td>
</tr>
<tr>
<td>Pre-Natal</td>
<td></td>
</tr>
<tr>
<td>HIV</td>
<td></td>
</tr>
<tr>
<td>Behavioral Health</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

2. Who is on the program team?
   - Physician champion: ________________________________________________________
   - Administrator: _____________________________________________________________
   - Providers: ________________________________________________________________
   - Nursing staff: ___________________________________________________________
   - Social Services: __________________________________________________________
   - Patient Navigator(s): _____________________________________________________
   - Other(s): ________________________________________________________________

3. On a scale of 1-5 with one being the lowest, what is the perceived team commitment?
   - 1  □  2 □  3 □  4 □  5 □

4. How will the program be funded?
   - Grants
   - Insurance
   - County/State Funding
   - Patient self-pay
   - Other: ________________________________________________________________

5. Which salaries will be supported by the program budget?

<table>
<thead>
<tr>
<th>Position</th>
<th>Full time/Part Time</th>
<th>Number of Hours/Week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Navigator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outreach Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administrative Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provider Champion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6. What additional expenses will be supported by the budget? □ Educational Materials □ Training
7. □ Travel Expenses □ Computers □ Software
   □ Other: ________________________________
8. Where will the Navigator be housed? ________________________________
9. What equipment will the Navigator need?
   □ Telephone □ Computer □ Fax □ Printer
   □ Other: ________________________________
10. What is the timeline for implementation?
    Start Date: ____________________
    Projected Implementation Date ____________

<table>
<thead>
<tr>
<th>Task</th>
<th>Responsible Person</th>
<th>Date Due</th>
<th>Progress</th>
<th>Date Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

11. How will patients be identified as eligible for the program?
    □ Provider Referral □ Pathology/Radiology/Surgical Reports □ Lab Value Parameters
    □ Hospitalizations/ER Visits □ Patient Non-adherence to Treatment Plan □ Self-Referral
    □ Disease State Specific □ Preventive Health Needs □ Other: ________________________________
12. What is your anticipated number of patients for patient navigation? _______________
13. What is your anticipated patient to navigator ratio? ________________________________

Patient Navigator Role:
1. Who do you envision in the role of the patient navigator?
   □ Nurse □ Social Worker □ Medical Assistant □ Lay Person □ Other: ________________
2. What are the primary functions you would like the patient navigator to fulfill?
   □ Community Outreach and Education □ Care Coordination □ Patient Education/Support
   □ Financial Counseling □ Other: ________________________________
3. What additional activities would you like the patient navigator to be involved in?
   □ Quality/Process Improvement □ Staff Education Programs □ Support Groups
   □ Reporting □ Health Fairs/Screening Programs □ Other: ________________________________
4. Where will the patient navigator document patient interventions? ________________________________

Resources:
1. What internal resources do you currently have in place?
   □ Financial Counseling □ Social Services □ Dieticians □ Home Care □ Palliative Care
   □ Genetic Counseling □ Behavioral Health □ Hospice □ Chaplin Services □ PT/OT
   □ Pharmacy □ Support Groups, Specify ________________________________
   □ Other, Specify ________________________________
2. What community resources do you currently have relationships with?
   □ Health Department □ Department of Social Services □ Food Banks □ Transportation
   Services □ Translation Services □ Support Groups, Specify ________________________________
   □ Other, Specify ________________________________
Other Considerations:
1. How will you measure the effectiveness of the program? □ Patient Health Outcomes □ Patient Costs □ Patient Experience Surveys □ Screening Rates □ Diagnostic Follow-up Rates □ Other: ____________________________

2. Will you need staff training prior to starting the program? □ Yes □ No
   If yes, who will provide training? ____________________________

3. Do policies and procedures need to be created and/or updated to support the program? □ Yes □ No

4. Based on your patient population are there any special considerations to meet their needs?

<table>
<thead>
<tr>
<th>Facility/Practice Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population</td>
</tr>
<tr>
<td>% Female</td>
</tr>
<tr>
<td>% Male</td>
</tr>
<tr>
<td>% 0-18</td>
</tr>
<tr>
<td>% 19-39</td>
</tr>
<tr>
<td>% 40-65</td>
</tr>
<tr>
<td>% 65+</td>
</tr>
<tr>
<td>% White</td>
</tr>
<tr>
<td>% African-American</td>
</tr>
<tr>
<td>% Asian, Pacific Islander</td>
</tr>
<tr>
<td>% American Indian</td>
</tr>
<tr>
<td>% Other</td>
</tr>
<tr>
<td>% Private Insurance</td>
</tr>
<tr>
<td>% Medicaid</td>
</tr>
<tr>
<td>% Medicare</td>
</tr>
<tr>
<td>% Uninsured</td>
</tr>
<tr>
<td>% Hispanic</td>
</tr>
<tr>
<td>% Non-Hispanic</td>
</tr>
<tr>
<td>% Unknown</td>
</tr>
</tbody>
</table>

5. Is there anyone else needed at the table? □ Yes □ No
   If yes, who? ____________________________

6. What are the challenges/barriers to a successful program?

______________________________________________
______________________________________________
______________________________________________

Completed by: __________________________________ Date: ____________________________
Appendix 9
Sample Job Description

Position Description

Position Title: Patient Navigator

Supervisory Responsibilities:
Budget Responsibilities:
Reports to:
FLSA:
Date:

Position Summary:

Patient Navigator is self directed and interacts professionally with a variety of people across multiple disciplines. He/she will demonstrate actions and attitudes that contribute to the critical success factors of patient navigation in a community setting. The position calls for effective communication with safety net clinic staff, providers, community organizations, and patients. It requires knowledge of the environment and system through which a patient must move in order to obtain care.

The Patient Navigator must be able to track and trend clinic progress and effectively communicate findings to clinic management and staff to promote screening services and follow-up to clinic patients.

Primary Responsibilities:
1. Assist in the identification of clinic patients eligible for navigation.
2. Assess patient’s ability to navigate through the healthcare system and identify possible barriers to diagnosis and treatment.
3. Provide patient/family with appropriate educational materials
4. Assist patient in scheduling appointments for routine, diagnostic and/or follow-up care.
5. Assist patient in overcoming financial barriers to obtaining appropriate screening/diagnostic testing and treatment.
6. Contact patients prior to appointments as needed.
7. Monitor the receipt of testing and consult results.
8. Follow-up with patient on results as directed by the provider.
9. Document significant patient navigation activities into the medical record.
10. Ensure coordination of care among treatment providers

Secondary Responsibilities:

1. Develop relationships with personnel and entities providing diagnostic and treatment services to the patient.
2. Participate in Quality Improvement activities as assigned.
3. Provide assistance to spread the learnings of patient navigation to other preventative and disease state patient navigation initiatives.
4. Assist in the training of co-workers.
5. Perform other duties as assigned.
Education and Experience:

1. Associates degree or equivalent experience in human service fields.
2. Minimum of 1 year experience in working with patients in a clinic setting.
3. Experience working with a diverse, multicultural population

Skills and Abilities:

1. Bilingual English and Spanish preferred
2. Critical thinking and problem solving skills
3. Ability to communicate clearly and concisely, orally and in writing.
4. Good organizational and time management skills.
5. Ability to maintain composure in stressful situations.
6. Competent in Microsoft Office and applicable software programs.
7. Demonstrate an understanding of and an appreciation for the physical, social and psychological needs of the population served.
8. Demonstrate a positive attitude.
## Build Your Question List

<table>
<thead>
<tr>
<th>Did you recently receive a diagnosis?</th>
<th>▶ What are the chances the treatment will work?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ask:</td>
<td>▶ Are there any side effects?</td>
</tr>
<tr>
<td>❖ What is my diagnosis?</td>
<td>▶ What can be done about them?</td>
</tr>
<tr>
<td>❖ What is the technical name of my disease or condition, and what does it mean in plain English?</td>
<td>▶ How soon do I need to make a decision about treatment?</td>
</tr>
<tr>
<td>❖ What is my prognosis (outlook for the future)?</td>
<td>▶ What happens if I choose to have no treatment at all?</td>
</tr>
<tr>
<td>❖ What changes will I need to make?</td>
<td></td>
</tr>
<tr>
<td>❖ Is there a chance that someone else in my family might get the same condition?</td>
<td>Are you scheduled to have medical tests?</td>
</tr>
<tr>
<td>❖ Will I need special help at home for my condition?</td>
<td>Ask:</td>
</tr>
<tr>
<td>❖ Is there any treatment?</td>
<td>❖ What is the test for?</td>
</tr>
<tr>
<td>❖ What are my treatment options?</td>
<td>❖ How is the test done?</td>
</tr>
<tr>
<td>❖ How soon do I need to make a decision about treatment?</td>
<td>❖ Will the test hurt?</td>
</tr>
<tr>
<td>❖ What are the benefits and risks associated with my treatment options?</td>
<td>❖ How accurate is the test?</td>
</tr>
<tr>
<td>❖ Is there a clinical trial (research study) that is right for me?</td>
<td>❖ Is this test the only way to find out that information?</td>
</tr>
<tr>
<td>❖ Will I need any additional tests?</td>
<td>❖ What are the benefits and risks of having this test?</td>
</tr>
<tr>
<td>❖ What organizations and resources do you recommend for support and information?</td>
<td>❖ What do I need to do to prepare for the test?</td>
</tr>
<tr>
<td>❖ How many times have you performed the test?</td>
<td>❖ How many times have you performed the test?</td>
</tr>
<tr>
<td>❖ When will I get the results?</td>
<td>❖ What will the results tell me?</td>
</tr>
<tr>
<td>❖ What’s the next step after the test?</td>
<td></td>
</tr>
</tbody>
</table>

### Are you considering treatment for an illness or condition?

<table>
<thead>
<tr>
<th>Ask:</th>
</tr>
</thead>
<tbody>
<tr>
<td>❖ What are my treatment options?</td>
</tr>
<tr>
<td>❖ What do you recommend?</td>
</tr>
<tr>
<td>❖ Is the treatment painful?</td>
</tr>
<tr>
<td>❖ How can the pain be controlled?</td>
</tr>
<tr>
<td>❖ What are the benefits and risks of this treatment</td>
</tr>
</tbody>
</table>

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[www.ahrq.gov/questionsaretheanswer](http://www.ahrq.gov/questionsaretheanswer)
### Build Your Question List (2)

<table>
<thead>
<tr>
<th>Did your clinician give you a prescription?</th>
<th>Did your clinician recently recommend surgery?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ask:</strong></td>
<td><strong>Ask:</strong></td>
</tr>
<tr>
<td>❖ What is the name of the medicine?</td>
<td>❖ Why do I need surgery?</td>
</tr>
<tr>
<td>❖ How do you spell the name?</td>
<td>❖ What kind of surgery do I need?</td>
</tr>
<tr>
<td>❖ Can I take a generic version of this medicine?</td>
<td>❖ What will you be doing?</td>
</tr>
<tr>
<td>❖ What is the medicine for?</td>
<td>❖ What are the benefits and risks of having this surgery?</td>
</tr>
<tr>
<td>❖ How am I supposed to take it?</td>
<td>❖ Have you done this surgery before?</td>
</tr>
<tr>
<td>❖ When should I take my medicine?</td>
<td>❖ How successful is this surgery?</td>
</tr>
<tr>
<td>❖ How much medicine should I take?</td>
<td>❖ Which hospital is best for this surgery?</td>
</tr>
<tr>
<td>❖ How long do I need to take the medicine?</td>
<td>❖ Will the surgery hurt?</td>
</tr>
<tr>
<td>❖ When will the medicine start working?</td>
<td>❖ Will I need anesthesia?</td>
</tr>
<tr>
<td>❖ Can I stop taking my medicine if I feel better?</td>
<td>❖ How long will the surgery take?</td>
</tr>
<tr>
<td>❖ Can I get a refill?</td>
<td>❖ How long will it take me to recover?</td>
</tr>
<tr>
<td>❖ Are there any side effects?</td>
<td>❖ How long will I be in the hospital?</td>
</tr>
<tr>
<td>❖ When should I tell someone about a side effect?</td>
<td>❖ What will happen after the surgery?</td>
</tr>
<tr>
<td>❖ Do I need to avoid any food, drinks, or activities?</td>
<td>❖ How much will the surgery cost?</td>
</tr>
<tr>
<td>❖ Does this new prescription mean I should stop taking any other medicines I’m taking now?</td>
<td>❖ Will my health insurance cover the surgery?</td>
</tr>
<tr>
<td>❖ Can I take vitamins with my prescription?</td>
<td>❖ Is there some other way to treat my condition?</td>
</tr>
<tr>
<td>❖ What should I do if I forget to take my medicine?</td>
<td>❖ What will happen if I wait or don’t have this surgery?</td>
</tr>
<tr>
<td>❖ What should I do if I accidentally take more than the recommended dose?</td>
<td>❖ Where can I get a second opinion?</td>
</tr>
<tr>
<td>❖ Is there any written information I can take home with me?</td>
<td></td>
</tr>
<tr>
<td>❖ Are there any tests I need to take while I’m on this medicine</td>
<td></td>
</tr>
</tbody>
</table>

[www.ahrq.gov/questionsaretheanswer](http://www.ahrq.gov/questionsaretheanswer)
### Build Your Question List (3)

<table>
<thead>
<tr>
<th>Are you choosing a clinician?</th>
<th>Are you choosing long-term care?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ask:</strong></td>
<td><strong>Ask:</strong></td>
</tr>
<tr>
<td>❖ Is this clinician part of my health plan?</td>
<td>❖ What kind of services do I need?</td>
</tr>
<tr>
<td>❖ Does this clinician have the background and training I need?</td>
<td>❖ What are my care options?</td>
</tr>
<tr>
<td>❖ Is this clinician able to work at the hospital I like?</td>
<td>❖ Will my health insurance cover long-term care?</td>
</tr>
<tr>
<td>❖ Can I talk to this clinician and ask questions easily?</td>
<td>❖ Will this facility meet my needs?</td>
</tr>
<tr>
<td>❖ Does this clinician listen to me?</td>
<td>❖ How is this care facility rated?</td>
</tr>
<tr>
<td>❖ Does this clinician wash his or her hands between examining each patient?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Are you choosing a hospital?</th>
<th>Are you choosing a health plan?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ask:</strong></td>
<td><strong>Ask:</strong></td>
</tr>
<tr>
<td>❖ Which hospital has the best care for my condition?</td>
<td>❖ What are my options?</td>
</tr>
<tr>
<td>❖ Is this hospital covered by my health insurance?</td>
<td>❖ Does this health plan provide the benefits and services I need?</td>
</tr>
<tr>
<td>❖ Does the hospital meet national quality standards?</td>
<td>❖ Does this health plan offer the clinicians and hospitals I want?</td>
</tr>
<tr>
<td>❖ How does the hospital compare with others in my area?</td>
<td>❖ Can I afford this health plan?</td>
</tr>
<tr>
<td>❖ Has the hospital had success with my condition?</td>
<td></td>
</tr>
<tr>
<td>❖ Does my clinician have privileges (is allowed to work) at this hospital?</td>
<td></td>
</tr>
<tr>
<td>❖ Is the treatment painful?</td>
<td></td>
</tr>
<tr>
<td>❖ How can the pain be controlled?</td>
<td></td>
</tr>
<tr>
<td>❖ What are the benefits and risks of this treatment?</td>
<td><a href="http://www.ahrq.gov/questionsaretheanswer">www.ahrq.gov/questionsaretheanswer</a></td>
</tr>
</tbody>
</table>
Appendix 11

Communicating with Patients

Communication has been defined as “the transmission of information, thoughts, and feelings so that they are satisfactorily received or understood.” Good patient communication involves recognizing and responding to the patient as a whole person—an approach frequently termed “patient-centered” care. It also involves recognizing that in any provider-client interaction two experts are present: the provider who has the clinical knowledge and the client who has the knowledge of the individual and cultural factors that influence effective treatment and care. The RESPECT model, presented below, crystallizes the patient-centered approach to communication.

THE RESPECT MODEL

Rapport
☐ Connect on a social level.
☐ See the patient’s point of view.
☐ Consciously suspend judgment.
☐ Recognize and avoid making assumptions

Empathy
☐ Remember that the patient has come to you for help.
☐ Seek out and understand the patient’s rational for his/her behaviors or illness.
☐ Verbally acknowledge and legitimize the patient’s feelings

Support
☐ Ask about and understand the barriers to care and compliance.
☐ Help the patient overcome barriers.
☐ Involve family members if appropriate.
☐ Reassure the patient you are and will be available to help

Partnership
☐ Be flexible with regard to control issues.
☐ Negotiate roles when necessary.
☐ Stress that you are working together to address health problems

Explanations
☐ Check often for understanding.
☐ Use verbal clarification techniques.

Cultural competence
☐ Respect the patient’s cultural beliefs.
☐ Understand that the patient’s view of you may be defined by ethnic or cultural stereotypes.
☐ Be aware of your own cultural biases and preconceptions.
☐ Know your limitations in addressing medical issues across cultures.
☐ Understand your personal style and recognize when it may not be working with a given patient

Trust
☐ Recognize that self-disclosure may be difficult for some patients.
☐ Consciously work to establish trust


48 Mutha S, Allen C, Welch M. Toward Culturally Competent Care: A Toolbox for Teaching Communication Strategies. 2002; San Francisco: Center for the Health Professions, University of California
Appendix 12

**WORDS TO WATCH – FACT SHEET**

Many people, even highly literate people, have trouble understanding words used in health care. In some instances, a word may be totally unfamiliar. In other cases, a word may be familiar, but the person may not understand it in a health care context. For example, upon hearing “keep your glucose in a normal range,” people know what normal means about a person, and they may have a range in their kitchen, but they may miss the intended concept in terms of health care. Even people who understand the concept may need more information than the phrase provides. They need to be told what glucose measurements are considered normal.

Words with a Latin or Greek prefix present special problems. The health science field is full of such words. Here is a small sampling: pre-op, post-op, prenatal, premature, unsweetened, decontaminate, antibacterial. For example, the risk factor for poor readers with diabetes is that they may recognize one part of the word, such as the sweetened in unsweetened, and then skip the un. This kind of guessing can lead to the opposite behavior.

Four kinds of words cause much of the misunderstanding:

- Medical words
- Concept words
- Category words
- Value judgment words

Often these kinds of words can be made understandable by explaining them with common words, by an example, or by a visual.

### Medical Word Examples:

**Problem Word** | **Consider Using**
--- | ---
Ailment | Sickness, illness, problem with your health
Benign | Will not cause harm; is not cancer
Condition | How you feel; health problem
Dysfunction | Problem
Inhibitor | Drug that stops something that is bad for you
Intermittent | Off and on
Lesion | Wound, sore; infected patch of skin
Oral | By mouth
Procedure | Something done to treat your problem; operation
Vertigo | Dizziness

### Concept Word Examples:

**Problem Word** | **Consider Using**
--- | ---
Active role | Taking part in
Avoid | Stay away from; do not use (or eat)
Collaborate | Work together
Factor | Other thing
Gauge | Measure; get a better idea of; test (dependent on context)
Intake | What you eat or drink; what goes into your body
Landmark | Very important (adj.); Important event; turning point (n.)
Option | Choice
Referral | Ask you to see another doctor; get a second opinion
Wellness | Good health; feeling good

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49 Ask Me 3, please visit www.npsf.org.
**Category Word Examples:** Words that describe a group or sub-set, and may be unfamiliar

<table>
<thead>
<tr>
<th>Problem Word</th>
<th>Consider Using</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity</td>
<td>Something you do; something you do often, like driving a car</td>
</tr>
<tr>
<td>Adverse (reaction)</td>
<td>Bad</td>
</tr>
<tr>
<td>Cognitive</td>
<td>Learning; thinking</td>
</tr>
<tr>
<td>Hazardous</td>
<td>Not safe; dangerous</td>
</tr>
<tr>
<td>High-intensity exercise</td>
<td>Use an example, such as running</td>
</tr>
<tr>
<td>Generic</td>
<td>Product sold without a brand name, like ibuprofen</td>
</tr>
<tr>
<td>Noncancerous</td>
<td>Not cancer</td>
</tr>
<tr>
<td>Poultry</td>
<td>Chicken, turkey, etc.</td>
</tr>
<tr>
<td>Prosthesis</td>
<td>Replacement for a body part, such as a man-made arm</td>
</tr>
<tr>
<td>Support</td>
<td>Help with your needs – for money, friendship, or care</td>
</tr>
</tbody>
</table>

**Value Judgment Word Examples:** Words that may need an example or visual to convey their meaning with clarity.

<table>
<thead>
<tr>
<th>Problem Word</th>
<th>Consider Using</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate</td>
<td>Enough</td>
</tr>
<tr>
<td></td>
<td><em>Example (adequate water): 6-8 glasses a day</em></td>
</tr>
<tr>
<td>Adjust</td>
<td>Fine-tune; change</td>
</tr>
<tr>
<td>Cautiously</td>
<td>With care; slowly</td>
</tr>
<tr>
<td></td>
<td><em>Example: making sure to hold on to handrails</em></td>
</tr>
<tr>
<td>Excessive</td>
<td>Too much</td>
</tr>
<tr>
<td></td>
<td><em>Example (bleeding): if blood soaks through the bandage</em></td>
</tr>
<tr>
<td>Increase gradually</td>
<td>Add to</td>
</tr>
<tr>
<td></td>
<td><em>Example (exercise): add 5 minutes a week</em></td>
</tr>
<tr>
<td>Moderately</td>
<td>Not too much</td>
</tr>
<tr>
<td></td>
<td><em>Example (exercise): so you don’t get out of breath</em></td>
</tr>
<tr>
<td>Progressive</td>
<td>Gets worse (or better)</td>
</tr>
<tr>
<td>Routinely</td>
<td>Often</td>
</tr>
<tr>
<td></td>
<td><em>Example: every week; every other day</em></td>
</tr>
<tr>
<td>Significantly</td>
<td>Enough to make a difference</td>
</tr>
<tr>
<td></td>
<td><em>Example (smoking/heart disease): 2 times the chance of having heart disease</em></td>
</tr>
<tr>
<td>Temporary</td>
<td>For a limited time; for about (an hour, day…)</td>
</tr>
<tr>
<td></td>
<td><em>Example: for less than a week</em></td>
</tr>
</tbody>
</table>
Appendix 13
Facilitating Behavior Change\(^{50}\)

Motivational interviewing is an approach, first reported in the addiction literature, to improve adherence (Miller & Rollnick, 2002); it is both an assessment strategy and an intervention. Motivational interviewing is used to determine a person's readiness to engage in a target behavior - such as taking a medication as prescribed - and then applying specific skills and strategies based on the person's level of readiness to create a favorable climate for change.

Motivational interviewing is a person-centered, directive method of communicating with the goal of enhancing a person's intrinsic motivation to change by exploring and resolving ambivalence and resistance (Miller & Rollnick, 2002). Motivational interviewing techniques try to avoid simply telling a person what they need to do. People can easily dismiss such suggestions or come up with a number of reasons why the suggested change is not possible.

The essence of motivational interviewing is in its collaborative nature, communicating in a partner-like relationship, where the interviewer seeks to create a positive interpersonal atmosphere. In motivational interviewing, responsibility for change is left to the person; the overall goal is to increase the person's intrinsic motivation, so that change arises from within rather than being imposed.

It must be recognized that it is the person, not the health care provider, who will ultimately need to make changes that will affect their health. Thus, change must be negotiated, not dictated. Consistent with the collaborative model, the health care provider functions not to motivate the person, but to draw out intrinsic motivation based on the person's own personal goals and values.

MOTIVATIONAL INTERVIEWING PRINCIPLES

Motivational interviewing uses a number of person-centered techniques to create a favorable climate for change. There are five general principles that underlie motivational interviewing (Miller & Rollnick, 2002). The key principles are arranged to form the acronym READS, to help providers remember these key concepts (Table 7). These principles are not necessarily applied in this particular order, and all of these techniques should be used throughout the interaction.

|------------------------|-------------------|-----------------------|----------------------|------------------------|

Roll with Resistance

Resistance can take several forms, such negating, blaming, excusing, minimizing, arguing, challenging, interrupting, and ignoring. In motivational interviewing one does not directly oppose resistance but, rather, rolls or flows with it. Direct confrontation will create additional barriers that will make change more difficult. A person's resistance during motivational interviewing is expected and should not be viewed as a negative outcome. In fact, a person who resists is providing information about factors that foster or reduce motivation to adhere to behavioral change. Rolling with resistance, then, includes involving the person actively in the process of problem solving.

Resistant behavior may be a signal that the person does not believe or accept information that has been presented. The health care provider should provide information and alternatives, and explore possible solutions. Exploring the reasons behind the resistant behavior can lead the person to seriously consider possibilities for change.

\(^{50}\) http://www.adultmeducation.com/FacilitatingBehaviorChange_2.html
Express Empathy

Because motivational interviewing relies to a great extent on establishing and maintaining rapport with the person, the ability to express empathy is critical to this process. This requires skillful, reflective listening to understand a person's feelings and perspectives without judging, criticizing, or blaming. An attitude of acceptance and respect contributes to the development of an effective, helping relationship and enhances the person's self-esteem. Empathic responses demonstrate that the health care provider understands the person's point of view and provides an important basis for engaging the person in a process of change.

Avoid Argumentation

Resistance to change is strongly affected by the health care provider's response; therefore, arguments should be avoided. Direct confrontations usually result in defensive reactions and increased resistance to change. Resistance is an indication that the health care provider should change strategies rather than argue. The emphasis should focus on helping the person with self-recognition of problem areas rather than coerced admission.

Develop Discrepancy

The principle of developing discrepancy is based on the understanding that motivation for change is created when the person perceives a discrepancy between their present behavior and important personal goals (Miller & Rollnick, 2002). This often involves identifying and clarifying the person's own goals. The goals need to be those of the person and not those of the health care provider, otherwise the person will feel as though they are being coerced and may become more resistant to change. An important objective of motivational interviewing is to help a person recognize or amplify the discrepancy between their behavior and their personal goals.

There are a number of techniques that can be used to help develop discrepancy. One technique is to ask the person what is good or positive about a particular behavior and what is bad or not so good about that same behavior. Reflecting back and examining the positive and negative will help discrepancy emerge. When skillfully done, motivational interviewing changes the person's perceptions of discrepancy without creating a sense of being pressured or coerced.

Support Self-Efficacy

Self-efficacy is a person's belief or confidence in their ability to carry out a target behavior successfully. A general goal of motivational interviewing is to enhance the person's confidence in their ability to overcome barriers and succeed in change.

Health care providers can support self-efficacy by recognizing small positive steps that the person is taking to change their behavior. Even when the person is simply contemplating a change, there is an opportunity to provide recognition and support. Supportive statements can be as simple as "It's great to hear that you are interested in getting more information about your diabetes."

Setting reasonable and reachable goals that the person can actually accomplish will also help build confidence. It is important that the person be involved in setting the goal. For an overweight person that is physically inactive, even getting them to exercise five to 10 minutes twice a week is a move in the right direction. Seeing that they can accomplish this will give them additional motivation to continue to exercise.

Lastly, it is important that the health care provider believes that the person can achieve the goal. This belief in the person can have a powerful positive effect on the outcome.
Elicit, Provide, Elicit

The person, not the health care provider, is the primary source of solutions for dealing with their medical problems. In order for the person to take responsibility for their own health, they need to become an active participant in sessions with their health care providers.

Elicit-Provide-Elicit Method

![Diagram showing the process of elicit, provide, elicit]

Motivational interviewing uses the general concept of elicit, provide, elicit, which is a continuous process. Information is elicited from the person so the health care provider can better understand their attitudes, beliefs, values, and readiness to change. The health care provider can check for understanding of what the person is saying by using reflective listening skills and asking for additional clarification when required; this will help establish a collaborative relationship and build empathy. Information elicited can also be used to help develop discrepancy.

After eliciting information, the health care provider can then provide information to address any knowledge gaps identified. It may be appropriate at times to ask permission from the person to provide them with additional information. This may increase acceptance of the information, as the person will not feel that information is simply being imposed on them.

Lastly, whenever the person is presented with new information, the health care provider should elicit information on the person's understanding of the new information and their feelings about it. This can identify concerns or questions that the person may have regarding the information presented.
Appendix 14

READINESS RULER

The Readiness-to-Change Ruler is used to assess a person’s willingness or readiness to change, determine where they are on the continuum between “not prepared to change” and “already changing”, and promote identification and discussion of perceived barriers to change. The ruler represents a continuum from “not prepared to change” on the left, to “already changing” on the right.

The Readiness-to-Change Ruler can be used as a quick assessment of a person’s present motivational state relative to changing a specific behavior, and can serve as the basis for motivation-based interventions to elicit behavior change. Readiness to change should be assessed regarding a very specific activity such as taking medications, following a diet, or exercising, since persons may differ in their stages of readiness to change for different behaviors.

Below, mark where you are now on this line that measures your change in __________________________________.

Are you not prepared to change, already changing or somewhere in the middle?

<table>
<thead>
<tr>
<th>Not prepared to change</th>
<th>Already Changing</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

Source: adultmeducation.com

ADMINISTRATION
1. Indicate the specific behavior to be assessed on the Readiness-to-Change Ruler form. Ask the person to mark on a linear scale from 0 to 10 their current position in the change process. A 0 on the left side of the scale indicates “not prepared for change” and a 10 on the right side of the scale indicates “already changing”.
2. Question the person about why he or she did not place the mark further to the left, which elicits motivational statements.
3. Question the person about why he or she did not place mark further to the right, which elicits perceived barriers.
4. Ask the person for suggestions about ways to overcome identified barriers and actions that might be taken.

SCORING
A score above 5 shows that the person is willing to consider change and should be supported and encouraged.

FOLLOW-UP QUESTION SUGGESTIONS

If the person’s mark is on the left of center:
• How will you know when it is time to think about changing?
• What signals will tell you to think about making a change?
• What qualities in yourself are important to you?
• What connection is there between those qualities and not considering a change?

If the person’s mark is near the center:
• Why did you put your mark there and not closer to the left?
• What might make you put your mark a little further to the right?
• What are the good things about the way you are currently trying to change?
• What are the things that are not so good?
• What would be a good result of changing?
• What are the barriers to changing?

If the person’s mark is on the right of center:
• What is one barrier to change?
• What are some things that could help you overcome this barrier?
• Pick one of those things that could help and decide to do it by ________________ (specific date).

If the person has taken a serious step in making a change:
• What made you decide on that particular step?
• What has worked in taking this step?
• What helped it work?
• What could help it work even better?
• What else would help?
• Can you break that helpful step down into smaller parts?
• Pick one of those parts and decide to do it by ________________ (specific date).

If the person is changing and trying to maintain that change:
• Congratulations! What’s helping you?
• What else would help?
• What makes it hard to maintain the change?

If the person has “relapsed”:
• Don’t be hard on yourself. Change is hard and may take time.
• What worked for a while?
• What did you learn that will help when you give it another try?

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52 Zimmerman et al., 2000.; adultmeducation.com
# Appendix 15

**Duke–UNC Functional Social Support Questionnaire (FSSQ)**

Here is a list of some things that other people do for us or give us that may be helpful or supportive. Please read each statement carefully and place an ‘X’ in the column that is closest to your situation. Give only 1 answer per row.

<table>
<thead>
<tr>
<th>Item</th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have people who care what happens to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I get love and affection.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I get chances to talk to someone about problems at work or with my housework.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I get chances to talk to someone I trust about my personal or family problems.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I get chances to talk about money matters.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I get invitations to go out and do things with other people.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I get useful advice about important things in life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I get help when I am sick in bed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: adultmeducation.
DUKE–UNC FUNCTIONAL SOCIAL SUPPORT QUESTIONNAIRE (FSSQ)

Social support in general, and the availability of help from family or friends, is positively associated with medication adherence. An assessment of a person’s perception of, and need for, a social support network can be as important as the person’s readiness to change when determining his or her level of motivation. The Duke-UNC Functional Social Support Questionnaire (FSSQ) is an eight-item instrument to measure the strength of the person’s social support network (Broadhead et al., 1988).

ADMINISTRATION
Ask the person to read each statement on the FSSQ and check the box that most closely matches his or her feelings about the question. There are five potential answers to each questions ranging from “As much as I would like” to “Much less than I would like.”
All questions must be answered to complete the scoring process.

SCORING
Responses to each question are scored on a 1 to 5 scale. “As much as I would like” receives a score of 5 and “Much less than I would like” receives a score of 1. The scores from all eight questions are summed (maximum 40) and then divided by 8 to get an average score. The higher the average score, the greater the perceived social support.

LIMITATIONS
The older person may score well on this questionnaire but have a single issue that will need to be resolved before he or she is ready to take steps to become adherent to their medication regimen. Also, this questionnaire will only help identify social support issues with the older adult; it will not resolve them. Some social support issues identified by the older adult may be very difficult to resolve.
Source: adultmeducation.com
## Prochaska and DiClemente’s Stages of Change Model

<table>
<thead>
<tr>
<th>Stage of Change</th>
<th>Characteristics</th>
<th>Techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-contemplation</td>
<td>Not currently considering change: &quot;Ignorance is bliss&quot;</td>
<td>Validate lack of readiness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Clarify: decision is theirs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encourage re-evaluation of current behavior</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encourage self-exploration, not action</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Explain and personalize the risk</td>
</tr>
<tr>
<td>Contemplation</td>
<td>Ambivalent about change: &quot;Sitting on the fence&quot;</td>
<td>Validate lack of readiness</td>
</tr>
<tr>
<td></td>
<td>Not considering change within the next month</td>
<td>Clarify: decision is theirs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encourage evaluation of pros and cons of behavior change</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Identify and promote new, positive outcome expectations</td>
</tr>
<tr>
<td>Preparation</td>
<td>Some experience with change and are trying to change: &quot;Testing the waters&quot;</td>
<td>Identify and assist in problem solving re: obstacles</td>
</tr>
<tr>
<td></td>
<td>Planning to act within 1 month</td>
<td>Help patient identify social support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Verify that patient has underlying skills for behavior change</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encourage small initial steps</td>
</tr>
<tr>
<td>Action</td>
<td>Practicing new behavior for 3-6 months</td>
<td>Focus on restructuring cues and social support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bolster self-efficacy for dealing with obstacles</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Combat feelings of loss and reiterate long-term benefits</td>
</tr>
<tr>
<td>Maintenance</td>
<td>Continued commitment to sustaining new behavior</td>
<td>Plan for follow-up support</td>
</tr>
<tr>
<td></td>
<td>Post-6 months to 5 years</td>
<td>Reinforce internal rewards</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discuss coping with relapse</td>
</tr>
<tr>
<td>Relapse</td>
<td>Resumption of old behaviors: &quot;Fall from grace&quot;</td>
<td>Evaluate trigger for relapse</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reassess motivation and barriers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Plan stronger coping strategies</td>
</tr>
</tbody>
</table>

## Appendix 17

### Patient Learning Assessment Tool

<table>
<thead>
<tr>
<th>Learner:</th>
<th>Preferred Method Of Learning:</th>
<th>List Major Learning Needs:</th>
<th>Possible Barriers to Learning:</th>
<th>Readiness to Change Stage:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Patient □ Spouse □ Parent □ Children □ Significant Other □ Guardian □ Caregiver</td>
<td>□ One to One □ Group Setting □ Classroom Instructions □ Demonstration □ Film/Video □ Written Instructions □ Brochures/Pamphlets □ Other</td>
<td>□ Diet □ Physical Activity □ Diagnostic Tests □ Disease Process □ Medications □ Treatment Options □ ADL’s □ Mental Health □ Medical Literacy</td>
<td>□ Vision Impairment □ Hearing Impairment □ Cultural/Religious □ Emotional □ Language □ Physical □ Cognitive □ Financial □ Time constraints □ Transportation □ No interest □ Other ____________</td>
<td>□ Unaware of problem, no interest in change □ Aware of problem, recognizes need for change □ Beginning to think of changes to make and recognizes benefits of change □ Actively taking steps toward change</td>
</tr>
</tbody>
</table>

Comments:

Provider Signature | Date: