

New Hampshire Colorectal Cancer Screening Program

Patient Navigation Model for Increasing Colonoscopy Quality and Completion

A Replication Manual



National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control



A Letter from New Hampshire



Dear Colleague,

Thank you for joining the fight to end suffering and death from colorectal cancer (CRC)! If you are reading this manual, you know that CRC can be prevented through high-quality screening, and that patient navigation (PN) is critical to our efforts.

With this PN model, you are committing your resources and energy to a research-tested approach shown to be effective. Navigation significantly increases adherence to screening and surveillance, reduces missed appointments, and increases completed colonoscopies that can find and remove polyps before they can potentially develop into cancer.

In my many years as a gastroenterologist, ***navigation is the only approach I have seen that resulted in colonoscopy completion by over 96% of patients.*** This outcome is particularly compelling since it was achieved in an underserved, low-income, uninsured population, many of whom did not speak English and some of whom were homeless. The genuine gratitude of the patients, and the realization that those with little or no access to care were successfully brought into the healthcare system, were a continual inspiration throughout the years of our program.

The importance of the work that you are doing cannot be overstated. Individuals from populations that are underserved, and those that experience health disparities in particular, experience significant barriers to screening that go beyond affordability. Navigation is the key to overcoming these barriers to critical healthcare.

We wish you and your team success and hope that your engagement with wonderful patients, and with Navigators and program staff who meaningfully improve public health through their excellence and passion for the work, will lead the way to eliminating colorectal cancer.

Here's to your success! We look forward to hearing your stories.

Warmest regards,

A handwritten signature in black ink that reads "Lynn F. Butterly, MD".

Lynn F. Butterly, MD
Principal Investigator, New Hampshire Colorectal Cancer Screening Program (NHCRCS)
Director, Colorectal Cancer Screening at Dartmouth-Hitchcock Medical Center
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Acknowledgements and Background

From 2009 to 2015, the New Hampshire Colorectal Cancer Screening Program (NHCRCS) carried out a statewide effort to increase high-quality colorectal cancer (CRC) screening. This effort included:

- Free colonoscopy screening for low-income, uninsured or underinsured state residents ages 50 through 64
- Connecting patients without a primary care provider to medical homes for comprehensive and continuous care
- Healthcare center partnerships to increase their use of evidence-based screening interventions
- A patient navigation (PN) intervention that was remarkably effective in increasing colonoscopy completion, based on results of a rigorous evaluation study led by the Centers for Disease Control and Prevention (CDC) in collaboration with NHCRCS staff

You should know . . .

The PN model is a key component of NHCRCS's successful colorectal cancer screening program. It is the focus of this manual.

For more information on NHCRCS

www.dhhs.nh.gov/dphs/cdpc/nhcrscsp.htm

CDC funded NHCRCS through a cooperative agreement with The Mary Hitchcock Memorial Hospital, acting as the bona fide agent of the New Hampshire Department of Health and Human Services. The Mary Hitchcock Memorial Hospital is part of Dartmouth-Hitchcock, a nonprofit academic health system caring for patients through affiliate hospitals and clinics in New Hampshire and Vermont.

CDC and NHCRCS worked to develop this manual, which will support others in replicating the NHCRCS PN intervention. We would like to acknowledge all of our national, state, and local partners for their invaluable contributions to the NHCRCS effort, especially:

- New Hampshire Department of Health and Human Services.
- Norris Cotton Cancer Center.
- NHCRCS Medical Advisory Board.
- NHCRCS Community Advisory Board.
- New Hampshire Federally Qualified Health Centers.
- New Hampshire Comprehensive Cancer Collaboration.
- New Hampshire State Cancer Registry.
- New Hampshire Health Systems Primary Care Practices.
- Participating Endoscopy Centers.
- The Mary Hitchcock Memorial Hospital/Dartmouth-Hitchcock.
- The American Cancer Society.

With special thanks to:

- NHCRCS Patients.
- NHCRCS Staff—Lynn Butterly, MD, Principal Investigator and Medical Director; Joanne Gersten, RN, MS, Program Director; Gail Sullivan, RN, Kortney Sommer, RN, and Virginia Umland, RN, Nurse Navigators; Linda Gray, Janene Robie, and Leah S. Sacket, Data Managers and Coordinators; Bruce Adams, Benjamin Markes Wilson, and Amy Chadburn, Dartmouth-Hitchcock Corporate Finance Department.

Before You Get Started

CDC and NHCRCSP are excited that you are exploring and perhaps adopting this successful patient navigation (PN) model. We wish you the best as you begin your work. There are some important things to consider as you proceed.

This manual describes how to implement the NHCRCSP PN model as it was originally designed and carried out by the program staff and evaluated by CDC. You should expect positive results if you implement the model as described in this manual. In other words, we strongly encourage you to replicate the PN model with fidelity. If you make significant modifications or eliminate any of the Core Elements described in this manual (reinvent the model) the intervention is no longer the NHCRCSP PN model and might not be as effective.

We hope this replication manual provides the guidance you need to plan, implement, and evaluate the NHCRCSP PN model. If, after using this manual, you have ideas to improve it, please let us know! We would also love to hear about your implementation—what is working and what challenges you have faced—and your results. Please send your comments, questions, and suggestions to NHPNManual@cdc.gov or NHCRCSP@Hitchcock.org.

CDC is supporting replication and further evaluation of the NHCRCSP model in new sites. By evaluating the model in new settings and with new populations, we will learn more about generalizability of the model's effectiveness. These evaluations will help us make the model and this manual even more practical and useful to those interested in implementing a PN intervention.

Note: NHCRCSP used PN to increase colonoscopy screening. We did not test the model with other colorectal cancer (CRC) screening tests, but this manual includes many resources that may be useful to navigation programs in which colonoscopy is not the primary screening test. In fact, information in the manual may benefit any PN program. If you use this manual with another CRC screening test or for another navigation purpose, we would love to hear from you.

The patient navigation model described in this manual was created by the New Hampshire Colorectal Cancer Screening Program (NHCRCSP) and developed through CDC grant number 5U58DP002053. It is copyright protected and not intended for commercial use or publication in part or in whole by any other parties without express written consent by NHCRCSP. The manual was developed by NHCRCSP and CDC and its dissemination is intended for use in public health.

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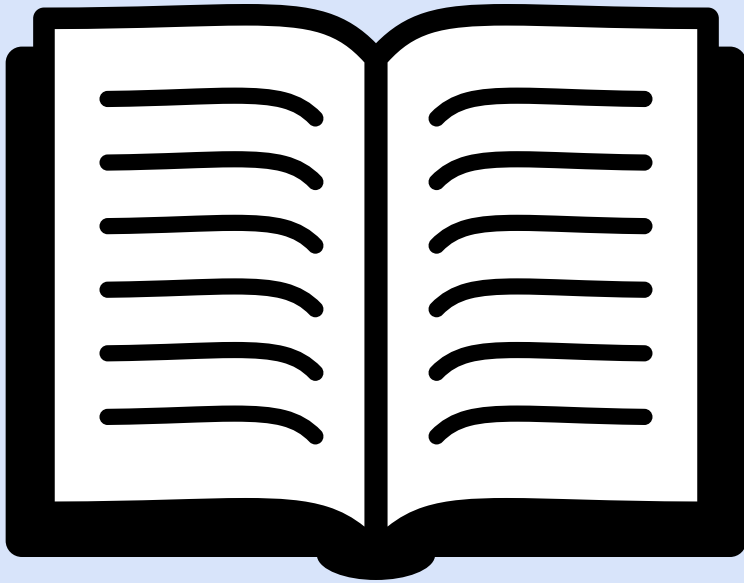
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1

Purpose and Use of This Manual



In This Section

- Rationale
- Intended Audiences
- Structure of the Manual
- Appendices

“I was amazed by the continuous contact throughout the entire process, including the congratulations card. It made my first experience unique and I was totally reassured. I will be able to tell people not to be afraid to be checked.”

NHCR CSP-Navigated Patient

Rationale

Colorectal cancer (CRC) is the second most common cause of cancer deaths in the United States among cancers that affect both men and women, despite the fact that it is preventable.¹ Screening and surveillance are effective ways to prevent CRC and to find it early, but screening rates remain relatively low, especially among low-income, uninsured, and underinsured individuals. The New Hampshire Colorectal Cancer Screening Program (NHCRCS) patient navigation (PN) model has been highly effective in increasing the completion and quality of colonoscopy screening among these groups. Given its success, CDC and NHCRCS developed this manual to help others replicate the NHCRCS PN model and expand its success.

Snapshot of NHCRCS Success over 6 Years

- 2 colonoscopy no-shows per 2,000 patients = 0.1% no-show rate
- Less than 1% inadequate bowel preparation in 2,000 patients
- 100% of patients received their test results and endoscopists' follow-up recommendations

This manual provides specific information and tools to replicate the NHCRCS PN model. We provide detailed information on implementing a model that improves completion of colonoscopy and follow-up, increases patients' knowledge about their tests and results, and improves overall quality of screening and patient satisfaction. We focus on the model itself and do not provide detailed description for development of a comprehensive CRC screening program such as NHCRCS.

Intended Audiences

Any organization that conducts CRC screening or administers a colonoscopy program may benefit from implementing this PN intervention. Organizations could include health systems, endoscopy centers, primary care practices (including Federally Qualified Health Centers), universities, or state and local health departments and grantee programs such as those funded by CDC and others. This manual also may be useful for healthcare providers, pharmacy staff, and other community partners to clarify their roles in the intervention and how it benefits their patients.

Structure of the Manual

- Section 1. Purpose and Use of This Manual
- Section 2. Patient Navigation
- Section 3. The NHCRCS Patient Navigation Model
- Section 4. Planning and Implementing a Successful Intervention
- Section 5. Using Data to Maintain a Quality Intervention

Appendices

This section provides additional tools and resource materials you may find helpful in planning, implementing, and evaluating your own PN intervention.

2

Patient Navigation



"I would like to give special thanks to [the Navigator]. If not for her, I would not have gone through the colonoscopy. Thank you so much."

NHCRCSP-Navigated Patient
(comment from the patient satisfaction survey)

In This Section

- Case for Colorectal Cancer Screening
- Barriers to Colorectal Cancer Screening
- Patient Navigation Overview

Case for Colorectal Cancer Screening

Studies have proven that colorectal cancer (CRC) screening reduces both cancer incidence and deaths.^{2,3} Average-risk individuals (those with no personal or family history of CRC or potentially precancerous polyps) can use a variety of screening tests recommended by the U.S. Preventive Services Task Force, but a colonoscopy must follow any positive test. Higher-risk individuals (those with a personal or close family history of CRC or significant polyps) should be screened by colonoscopy. Colonoscopy can prevent CRC or find it at earlier, more treatable stages. CRC almost always develops from abnormal growths called polyps on the lining of the large intestine (colon). During a colonoscopy, a doctor examines the entire colon and rectum, looking for polyps in order to remove them (polypectomy) before they can potentially develop into cancer. In cases where cancer cannot be prevented, colonoscopy helps to find cancers early, when treatment works best and survival rates are better.

What is a screening test?

Screening tests aim to prevent disease or find it early in people who do not have symptoms or signs of disease.

Diagnostic tests aim to find the cause when a person has symptoms or signs.

www.cdc.gov/cancer/colorectal/basic_info/screening/

If every U.S. adult ages 50 to 75 years were screened as recommended, we could prevent many deaths from CRC. In fact, screening 80% of adults aged 50 to 75 years by 2018 (the goal of the National Colorectal Roundtable's 80% by 2018 initiative) would prevent an estimated 277,000 CRC cases and 203,000 deaths from CRC by 2030.⁴ However, data collected in 2014 show that 34.3% of U.S. adults are not up-to-date on CRC screening, and 28% have never been screened.⁵ Many people who have insurance do not take advantage of CRC screening.⁶ Racial and ethnic minorities and people with lower education and income are even less likely to be screened. There is a critical need for interventions to increase both access to and use of CRC screening.

Barriers to Colorectal Cancer Screening

All CRC screening can present barriers to completion, and colonoscopy can pose more barriers than other screening tests. This can cause people to delay screening or completely avoid it. However, colonoscopy is the only test that allows polyp removal. Colonoscopy is also the best test for individuals at increased risk and the only indicated test for those who have had other positive screening tests. Therefore, it is crucial to understand and help patients overcome barriers to colonoscopy.

A complex mix of barriers can affect CRC screening. Some of the most common barriers to completing colonoscopy include:⁷⁻¹¹

- Belief that screening is not needed (no symptoms and no family history).
- Bowel preparation (prep) unpleasant/Not understanding how to take the bowel prep.
- Challenges related to child or elder care.
- Difficulty getting time off work for the prep and the procedure.
- Discomfort.
- Embarrassment/Modesty.
- Fear of results/Fatalism about cancer.
- Fear of procedure.
- Geographically too far from endoscopy site.

- Homelessness.
- Inability to identify someone to accompany the patient home on test day.
- Lack of knowledge about colonoscopy.
- Lack of knowledge about CRC and the need for screening.
- Lack of transportation to and from the procedure.
- Mistrust of the medical system.
- No insurance or being unaware that most insurance covers CRC screening with no out-of-pocket costs under the Affordable Care Act.
- No medical home.
- Other priority health issues.
- Provider did not recommend screening.

Note: This list of barriers is alphabetical; the order does not imply the relative importance of each barrier. Studies indicate, however, that the most common reasons patients give for not being screened are that they “did not know I needed it” and “my provider didn’t recommend it.”

Patient Navigation Overview

Patient navigation (PN) can help people at any point in the cancer continuum, from prevention to treatment and survivorship. It is an effective strategy to overcome patient barriers and get patients screened, and it contributes to high screening quality (tests that are done well). PN can be extremely useful in increasing CRC screening rates, which can decrease CRC incidence and mortality.

Patient navigation for cancer screening is individualized assistance to help patients overcome personal and healthcare system barriers, and to facilitate understanding and timely access to quality screening.

Twenty-five years ago, PN emerged as an effective way to address differences in cancer care (disparities) that are rooted in poverty.¹² In 1990, Dr. Harold Freeman with the Harlem Hospital Center in New York City pioneered the first PN program. His aim was to remove the barriers to breast cancer screening and treatment that low-income women faced by providing free and low-cost mammograms and PN. The Navigators provided individualized support to help each woman identify and overcome the barriers she faced in dealing with the medical system. With support from the Navigators, more low-income women had mammograms and completed diagnostic procedures at Harlem Hospital Center. A major outcome was the decrease in the number of women diagnosed with late-stage breast cancer.¹³

PN has become a critical tool in increasing screening and treatment for CRC and other types of cancer in the years following Dr. Freeman’s first breast cancer program.¹⁴ Since colonoscopy is a complex clinical procedure, programs have used PN specifically to help patients complete the test. The Guide to Community Preventive Services (the Community Guide) is a resource to help programs choose effective interventions to improve health and prevent disease in communities. While the Community Guide does not identify PN as a separate evidence-based intervention in its Cancer Prevention and Control topic area, it does include PN in the “reducing structural barriers” intervention recommended for colorectal and breast cancer screening (www.thecommunityguide.org/cancer/). PN also can enhance other Community Guide cancer screening interventions, such as client reminders and provider recall and reminder systems.

3

The NHCRCSP Patient Navigation Model



“If others understand and operationalize the core elements of the NHCRCSP patient navigation model and closely follow the 6-topic protocol, I’m confident the intervention can be successfully replicated.”

CDC staff person

In this section

- Overview of NHCRCSP
- Patient Enrollment in NHCRCSP
- The NHCRCSP Patient Navigation Model
- Core Elements of the NHCRCSP Patient Navigation Model
- Adapting the NHCRCSP Patient Navigation Model
- PN and Colonoscopy Preparation
- When Patient Navigation Services End
- The NHCRCSP Patient Navigation Six-Topic Protocol

Overview of NHCRCSP

This chapter details the PN model used by NHCRCSP to increase colonoscopy completion rates. The NHCRCSP team developed a screening and surveillance program, including the PN model, to fit the needs of their priority population, the mixed rural and urban nature of the state, and the intent to have a statewide program. Funded by CDC's Colorectal Cancer Control Program (CRCCP) (www.cdc.gov/cancer/crccp/) in 2009, the NHCRCSP had two main goals:

- Increase high-quality CRC screening throughout the state.
- Decrease screening disparities by providing free screening colonoscopies and PN to low-income, uninsured, or underinsured individuals.

Patient Enrollment in NHCRCSP

The patients served by NHCRCSP were New Hampshire residents who met CDC eligibility requirements for age (50 to 64), income (<250% of the federal poverty level), and insurance (un- or underinsured). Colonoscopy was used as the screening test given cost and access barriers for the priority population. As part of the CDC-funded program, NHCRCSP provided PN to every enrolled patient and paid for their colonoscopies.

Patients came to NHCRCSP primarily by self-referral or referral from a primary care provider (PCP) or another program such as CDC's National Breast and Cervical Cancer Early Detection Program. A program staff person, usually the Administrative Assistant, conducted patient intake by telephone, assessing the patient's basic eligibility. This staff person entered the patient's information into the NHCRCSP data system and mailed him or her an enrollment packet.

The enrollment packet included:

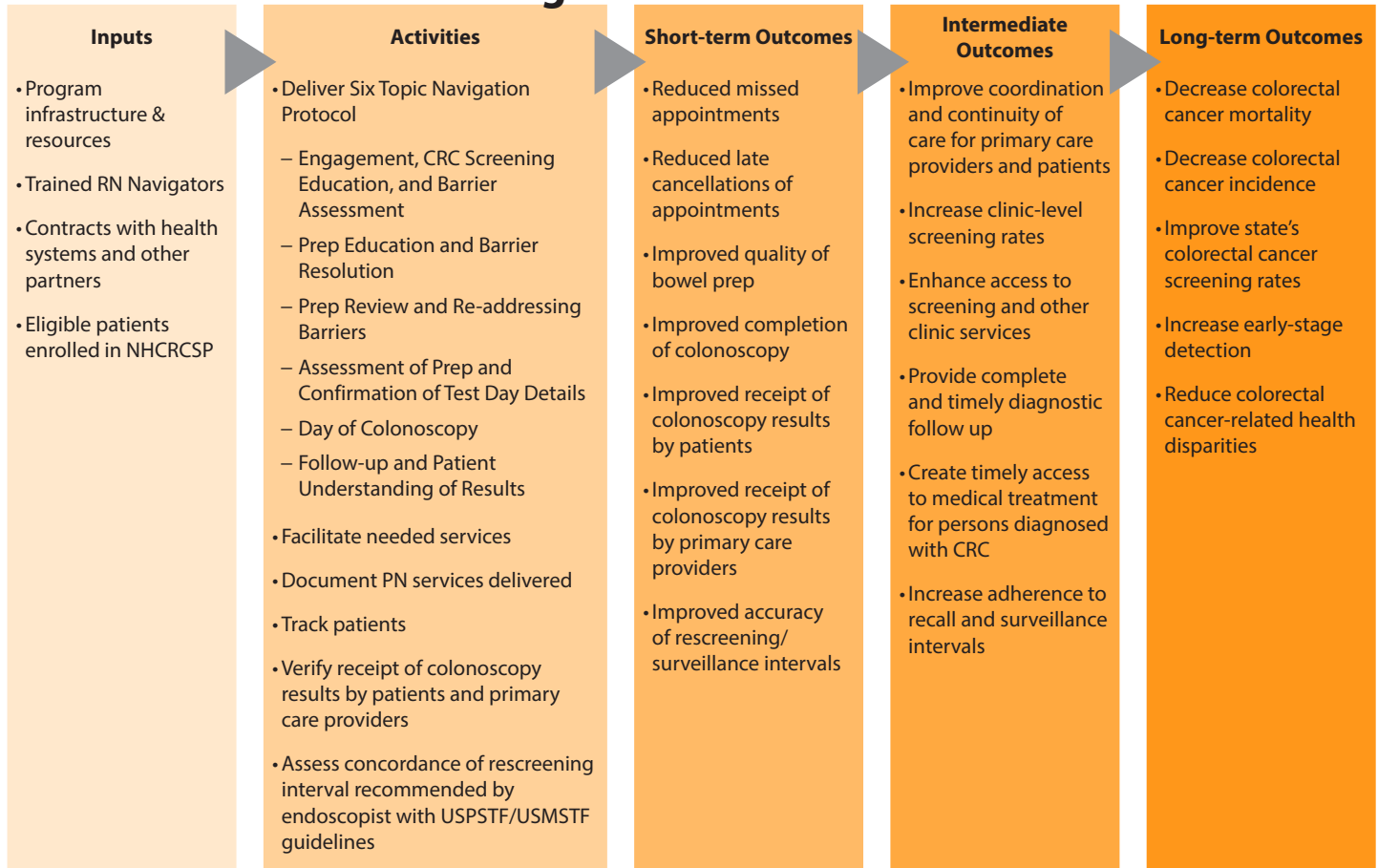
- Information about PN.
- CDC educational brochures on CRC and colonoscopy.
- Consent form for participation.
- Enrollment Form for patient to provide their medical history (see [Appendix A: NHCRCSP Sample Enrollment Form](#)).
- Authorization Form for the Use/Disclosure of Protected Health information (allowed the PCP and endoscopist to release patient information to NHCRCSP) for the patient to sign and return with the Consent and Enrollment Forms.

In addition to the patient's completion of the Enrollment Form, the program required a PCP visit within the last year for each patient. The PCPs filled out an NHCRCSP Referral Form detailing the patient's medical history, included a recent history and physical, and signed the form to confirm that the patient was medically cleared and appropriate for outpatient endoscopy (see [Appendix B: NHCRCSP Sample Primary Care Provider Colonoscopy Referral Form](#)). If a patient had not had a PCP visit within the past year, NHCRCSP paid for the visit and assisted the patient with obtaining a medical home. The Administrative Assistant obtained previous CRC screening test results (usually a colonoscopy) and pathology reports to ensure the patient was due for screening or surveillance.

All patient information (including the patient medical history, the PCP referral, and prior testing reports) was entered into the NHCRCSP data system. Then the Program Director, with support from the Medical Director, made the enrollment eligibility decision and assigned patients to a contracted endoscopy site in

the patient’s area and to the NHCRCSP Navigator who worked with patients using that endoscopy site (see [Appendix C: NHCRCSP Sample Patient Navigation Welcome Letter](#)). Navigators used all the information collected from the enrollment process in navigating their patients. In addition to navigating enrolled patients, NHCRCSP Navigators also guided patients who were ineligible for the program due to medical reasons to other resources.

The NHCRCSP Patient Navigation Model



CDC collaborated with the NHCRCSP team to conduct a rigorous evaluation of the NHCRCSP PN model from 2013 to 2016. This logic model describes the intervention and served as the basis for the evaluation. To assess the effectiveness of PN for key outcomes identified in the logic model, the team compared NHCRCSP-navigated patients to a similar group of non-navigated patients at one endoscopy center (see [Appendix D: The Evidence for the NHCRCSP Patient Navigation Model](#) for more detail on the evaluation study).

Results of the comparison study showed that the navigated patients were:

| | | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  <p>11 times more likely to complete colonoscopy than non-navigated patients.</p> |  <p>40 times less likely to miss the colonoscopy appointment.</p> |  <p>6 times more likely to have adequate bowel prep than non-navigated patients.</p> |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Core Elements of the NHCRCSP Patient Navigation Model

Seven Core Elements form the foundation of the NHCRCSP PN model and are crucial to its success. The Navigators' education, training, skills, and attributes are central to the intervention. The Core Elements provide the infrastructure and support needed by the Navigators to help patients complete colonoscopy successfully. Although replicating the program with fidelity (staying true to the original design) may be difficult, adhering to the Core Elements is essential to program success. A description of each of the Core Elements follows.



Core Element 1: Nurse Navigators. Navigators are the heart of the NHCRCSP PN model, which was specifically developed to recognize and resolve patient barriers to all aspects of colonoscopy. NHCRCSP chose registered nurses as Navigators because their **clinical expertise** minimized the training necessary for the position, and patients viewed nurses as credible and trusted sources of information. Nursing expertise allows the Navigators to understand the medical issues that are considered prior to a colonoscopy, such as heart disease or the use of anticoagulants. **Psychosocial assessment skills** allow NHCRCSP Navigators to understand each patient's barriers and problems. The Navigators "meet patients where they are," demonstrating respect and empathy, and are sensitive to unique cultural issues for individual patients.

The Navigators' engaging and supportive approach helps to build meaningful and trusting relationships in a very short time, usually during the first or second patient phone call. This ability to communicate effectively with patients enhances patient education and assists with problem solving to overcome identified barriers. **Organizational skills** are important to deliver the [six-topic protocol](#) consistently (Core Element 5), while juggling many patients at different stages of the navigation process. This combination of traits and abilities allow the Navigators to use the NHCRCSP PN processes and supports to achieve highly effective results. Centralizing navigation and Navigator support in the NHCRCSP promotes the consistent delivery of a quality program throughout the state.



Core Element 2: PN Champion with Clinical Expertise. Having a Champion is vital to your PN intervention. Internally, he or she ensures there is organizational support and program integrity. Externally, the Champion promotes the program's vision and value to potential partners and other stakeholders. The Champion is someone who is respected and has credibility among the healthcare community, and is a committed advocate for the program. The Champion and Medical Director can be a single individual (as in NHCRCSP) or two different people, but both roles are Core Elements. Key qualities for a PN Champion include leadership, passion, charisma, and expertise in CRC screening.



Core Element 3: Medical Oversight of the Navigation Intervention. The program should have a Medical Director or Medical Advisor with significant clinical expertise in endoscopy and CRC screening who oversees the details and quality of the navigation. The Medical Director can be a "door opener" to engage clinical sites, and should have the expertise to interact directly with endoscopists and primary care providers as a credible expert. Clinical oversight and guidance are essential features of successful navigation, and Navigators require consistent access to a supportive Medical Director with relevant expertise and experience. The Medical Director also provides important training and ongoing Navigator mentoring that specifically addresses colonoscopy and other screening tests, strategies to navigate barriers, and effective communication with patients.



Core Element 4: Partnerships. The PN intervention team must develop and sustain strong working relationships with endoscopy center staff, primary care providers, and other partners. Just as the Navigators build strong relationships with their patients, the Navigators also must have professional relationships with partners and people who play a role in their patients' care. Establishing meaningful working relationships with staff at endoscopy centers, for example, allows the Navigators to be strong patient advocates, ensuring that endoscopy staff are aware of patient needs such as cultural or language barriers, even when the Navigators themselves are not present in the endoscopy center. Each NHCRCSP Navigator worked with specific endoscopy centers, developing relationships with staff at those locations. Similarly, relationships with primary care practices, pathology laboratories, anesthesia providers, pharmacies, transportation services, and translators can improve patient care. Successful partnering ensures good communication, efficiency, and quality of care. Recognizing and appreciating the efforts of endoscopy center personnel to enhance the patient experience also helps the Navigator to ensure good care for patients. Key characteristics of an effective partner relationship include professionalism, expertise, credibility, consistency, appreciation and recognition, and a supportive attitude.



Core Element 5: [Six-Topic Navigation Protocol](#). Navigators follow an established protocol to deliver six important topics **by telephone** to patients at defined time intervals in the screening process. The six-topic protocol incorporates comprehensive patient education, assessment and resolution of patient barriers, patient coaching and encouragement, and timely reminders. The complete protocol is detailed at the end of this section, and we encourage users to print this section for Navigators. The prep is a critical aspect of the protocol, since a good prep is essential for colonoscopy. The important role of Navigators in supporting good prep is discussed later in this section.

The *content* of the calls and the Navigator-patient *relationship* developed during these calls are critically important, as opposed to simply the *number* of calls. Twenty calls would be ineffective if the Navigator does not cover the content (six topics) and if a relationship is not established between the Navigator and the patient. Some patients will need more calls from the Navigator than others to work through the process, especially during bowel prep. The number of calls for each topic would vary depending on a patient's ability to understand and follow instructions.

The NHCRCSP Navigator recorded the details of each call in a real-time data system (similar to a log) that each member of the NHCRCSP PN team could access at all times. Each patient was given the Navigator's dedicated (work) cell phone number and could call for additional help, although this extra assistance was rarely required. The program did not use text messages, and used e-mail only for setting up a date and time for a phone call, if the patient agreed.



Core Element 6: An Effective Data System. Having a comprehensive and secure data system to collect information needed to support patient tracking, patient care, quality monitoring, and evaluation is essential (See [Appendix E: Patient Navigation Intervention: Suggested Data Variables](#)). The NHCRCSP intervention team used a real-time data system to track patients, communicate with each other, document service delivery, and monitor outcomes. Team members had access to the data as soon as information was recorded, and they could access the data system simultaneously. This allowed the Program Director and Navigators to manage and plan their daily work together. The team used the data system to support day-to-day operations, make sure the team carried out the intervention as planned, and assess whether the program achieved its desired outcomes.



Core Element 7: Philosophy of Shared Success. A philosophy of success shared by the Navigator and patient is a guiding principle of the NHCRCSP PN model. The entire NHCRCSP team exemplified this philosophy. Although NHCRCSP Navigators addressed patient concerns and connected patients with needed services, they also helped patients learn how to manage the healthcare system and feel more comfortable taking responsibility for their own health. Navigators coached patients to accomplish tasks like filling out forms, making and cancelling appointments, and picking up the bowel prep from a pharmacy; the Navigators did not complete these tasks for the patients. The intent was for patients to understand the purpose of CRC screening and be motivated to take responsibility for completing the process themselves. At the end of the colonoscopy experience, navigated patients were better prepared to take a more active role in their overall healthcare.

Adapting the NHCRCSP Patient Navigation Model

You can adapt the intervention to the needs of your particular patient population or setting without altering the Core Elements that make the NHCRCSP model so effective. The following examples describe adaptations that may fit the characteristics of your patients and your organization, while staying true to the original intervention.

Location of Navigators: The Navigators may be located in various settings (a central location within a program site, office or primary care practice setting, endoscopy center, or teleworking from home).

Mode of Patient Communication: Some patient contacts could be face-to-face rather than by telephone.

Priority Populations: The priority populations for CRC screening should reflect the clinic or practice population, or the community served (rural or urban composition, racial or ethnic makeup, current screening rates, diversity in languages, cultural, and other factors). Designed for the uninsured population, the NHCRCSP-eligible patient group included adults ages 50 to 64; however, navigation can be expanded to include older adults.

Indications for the Colonoscopy: The NHCRCSP PN model primarily served patients who were due for a screening or surveillance colonoscopy, in accordance with CDC grant guidelines. Other programs could expand their eligibility for PN to include people needing colonoscopy for other reasons, such as screening following any other positive CRC screening tests (for example, stool tests or computed tomographic colonography [CTC]), or to those who need diagnostic colonoscopy to evaluate symptoms.

Other CRC Screening Tests: You can adapt this PN model for use with other CRC screening tests since quality and patient adherence are central to any successful CRC screening test. An effective fecal testing program depends on a series of procedures: the patient completes and returns the test; if the test is positive, the patient receives a colonoscopy; and, if the test is negative, the patient must repeat it at the appropriate interval. This PN model could likely assist with all steps in this process.

Geographic Reach: NHCRCSP served patients across the state. Your intervention could serve a targeted geographic area where screening rates are low, or you could serve the patients of a specific clinic population or practice (such as the patients of one or more specific health system or endoscopy center).

Type of Data System: You may not have access to a real-time data system like the one used in the NHCRCSP; in this case, an alternative data system is needed that is capable of supporting patient tracking, recording

program activities, and monitoring processes and results. For example, a secure spreadsheet software or browser-based content management platform could be designed for patient tracking and data collection. It may not have the same functionality of the system used by NHCRCSP to produce a full range of customized reports for managing daily activities; however, calendars and other reminder systems used in combination with spreadsheet software could work to track patients effectively and contact them at appropriate times (see [Section 5. Using Data to Maintain a Quality Intervention](#)).

Many possible database models exist that can support PN. Be sure that you understand your database and support system needs, and then adapt or create a system that addresses your goals and program structure.

PN and Colonoscopy Preparation

A good prep is *essential* to a quality colonoscopy, and should be considered as you plan, implement, and evaluate your program (see [Appendix F: NHCRCSP Sample Colonoscopy Preparation Instructions](#)). Navigators can play a critical role in ensuring the quality of colonoscopy bowel prep. Consequently, prep is a major focus within the [six-topic protocol](#). There are many types of prep and different schedules for taking the prep, so as part of program planning, staff and partners must agree on using the most effective prep. Studies show that a “split-prep”—taking part of the prep the afternoon and evening before, and part on the morning of the procedure—is the most effective choice.^{15–17} Before the NHCRCSP intervention began, the Medical Director discussed the type of prep with endoscopy leaders at each site to gain agreement on the most effective and safe prep, and on which prep would be used.

Because the prep can be difficult for many patients, Navigator expertise with strategies to help patients complete the prep is extremely important. These prep “tips and tricks” should be part of Navigator training and be a central part of conversations about prep with patients as part of the [six-topic protocol](#). Patients may have predictable issues with taking the prep, and Navigators should be familiar with solutions. NHCRCSP developed a YouTube prep video to assist patients (www.youtube.com/watch?v=xd1N0WOcd5A).

Other important aspects of prep education include delivering accurate and consistent instructions and translating instructions into languages spoken by your patient population. The Navigator, staff with the endoscopy center, pharmacist, prescription, and other written materials included in the patient information package all must promote the same prep and deliver consistent instructions. If a patient takes the prep incorrectly, he or she might have an inadequate prep and require a second colonoscopy. This duplication depletes limited resources. The need for language translation with written and verbal prep instructions will depend on your assessment of the priority population to be served with your program. In NHCRCSP, prep instructions were translated into 26 languages.

The endoscopist will score the prep quality; a few different scoring systems are currently in use. Scoring systems are fundamentally similar in that they are all intended to convey the likelihood that important lesions (such as polyps) might have been missed. If prep scoring will be important to your evaluation and/or among the outcomes you assess, clarify the scoring system used by endoscopists who are part of your program. Also, ensure that endoscopists record prep quality as part of the colonoscopy report, so that your program can retrieve that information.

For information about colonoscopy quality, see [Appendix G. Colonoscopy Quality Assurance](#).

When Patient Navigation Services End

As evident in the [six-topic navigation protocol](#), NHCRCSP PN services did not end when the colonoscopy was completed. Communication with the patient (and sometimes the endoscopy center) continued for several weeks after the exam to confirm the patient received screening results and appropriate follow-up recommendations from the endoscopist. The Navigators reviewed all endoscopy results and recommendations for future screening or surveillance with the Medical Director to ensure the follow-up recommendations were appropriate and consistent with screening guidelines, contacting the endoscopist for discussion if needed to resolve a discrepancy (see the current guidelines from the U.S. Preventive Services Task Force at www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/colorectal-cancer-screening2 and the U.S. Multi-Society Task Force on Colorectal Cancer at www.guideline.gov/summaries/summary/38454/).

When other problems related to screening arose, the Navigator continued to support the patient to ensure high-quality, complete screening. Patients occasionally had incomplete colonoscopies (needing a repeat procedure) due to inadequate prep, or due to procedural issues that made it difficult to examine the full colon, or due to an incomplete polypectomy (polyp removal). In these situations, the Navigator continued to work with the patient until the screening process (usually a repeat colonoscopy) was complete. If a patient was diagnosed with cancer, the Navigator ensured that the patient successfully accessed cancer care services. Patients also knew they could contact the Navigator in the future for any screening problems or questions.

The NHCRCSP Six-Topic Navigation Protocol

Preparation for Topic 1

Must be complete before first call to patient.

- Review all patient information including the enrollment form, CRC screening history, and primary care provider (PCP) referral.
- Confirm enrollment and add a note to data system: "Patient meets all enrollment criteria."
- Document family and personal CRC history in data system note.
- Check patient's primary language and arrange for translation service if needed.

1

Engagement, CRC Screening Education, and Barrier Assessment

Call and reach patient within 5 to 7 business days of Navigator assignment.

- Begin to establish rapport with the patient.
- Gain agreement on having a colonoscopy and on the six protocol topics.
- Review program, including PN, purpose, and content of calls.
- Discuss the purpose of a colonoscopy and explain the procedure.
- Ask patient questions to assess understanding of procedure and prep.
- Review the patient's medical history, make needed updates in the data system.
- Verify receipt of written colonoscopy prep instructions in patient's primary language.
- Have patient fill in the top part of the prep instructions with Navigator's phone number, endoscopy site address and phone number, and number to call to reschedule (see [Appendix F: NHCRCSP Sample Colonoscopy Preparation Instructions](#)).
- Discuss pharmacy the patient will use to obtain prep and transportation to pharmacy.
- Confirm the best time of day and best phone number to contact the patient.
- Ask for an emergency contact number and record that number in the data system.
- Assess barriers to colonoscopy, especially phone access, and transportation to and from procedure. Discuss solutions to overcome the barriers.
- Set date and time for the next call; tell the patient to contact you sooner, if needed.
- Ask the patient to leave you a voice mail with the time and date of the appointment.

Navigator Follow-up

- Update notes in data system.
- Document the patient barriers and determine resources needed to overcome them.
- Address resource barriers for patient.
- Record which pharmacy patient will use for prep, colonoscopy date and time, if known.

2

Prep Education and Barrier Resolution

Call and reach patient at least 5 to 7 days prior to the procedure.

- Continue to build trust with the patient.
- Confirm colonoscopy date, location, and time.
- Discuss arrangements for patient to get prep. Confirm specific pharmacy and when the patient will pick up the prep.
- Address any transportation barriers to pharmacy.
- Review prep instructions in detail, using the document the patient received in his or her primary language.
- Review what to have on hand for the day of prep, tips to make it easier, what to do if difficulties arise, and any barriers to following the instructions.
- Assess understanding of prep by asking the patient questions as you discuss the instructions.
- Offer link to YouTube prep video, [Colonoscopy Prep: Tips and Tricks \(www.youtube.com/watch?v=xd1N0WOcd5A\)](https://www.youtube.com/watch?v=xd1N0WOcd5A). If the patient does not have Internet access, send a DVD if they have access to a DVD player.
- Re-address potential barriers to colonoscopy through questions and discussion.
- Confirm patient has someone to accompany him/her to the procedure, and reconfirm emergency contact if information from top of prep form has changed (see information on [Appendix F: NHCRCSP Sample Colonoscopy Preparation Instructions](#)).
- Set date and time for next call; tell the patient to contact you sooner if needed.

Navigator Follow-up

- Update notes in data system including any new barriers, resources to overcome barriers, change in details of colonoscopy appointment, and date and time of next call.
- Document that you told the patient to contact you sooner if needed.
- Document any questions the patient may have that should be re-addressed on next call.
- List resources patient may need to overcome barriers or medical issues, for discussion on next call.

3

Prep Review and Re-addressing Barriers

Call and reach patient 1 to 2 days prior to start of the prep.

- Confirm prep pickup at pharmacy and understanding of instructions.
- Ask patient what their diet will be the day before and day of procedure, and review instructions for taking prep solution and for diet.
- Review morning-of-procedure instructions including when to stop the prep before travel.
- Re-address barriers and questions from the last call.
- Confirm who will accompany the patient home from the procedure and transportation to and from the endoscopy site.
- Confirm patient has endoscopy center contact number for day of procedure if he or she needs to cancel or has questions for the endoscopy center (rather than the Navigator).
- Call the Medical Director if there are any challenges with prep or you are unsure of other medical issues that have developed.
- Set the date for the next call and tell the patient to contact you sooner if needed.

Navigator Follow-up

- Update notes in data system.
- Document any new patient barriers.

4

Assessment of Prep and Confirmation of Test Day Details

Call and reach patient or leave voice mail the evening before the procedure.

- Discuss how the prep is going and review the next morning's prep and diet instructions.
- Answer any questions, provide support, and offer strategies to complete prep.
- Confirm the appointment time, address and name of endoscopy facility, and transportation to and from the endoscopy site.
- Tell patient you will call him or her tomorrow evening after the test.
- Re-address barriers and questions from the last call.
- Confirm who will accompany the patient home from the procedure and transportation.
- Confirm patient has endoscopy center contact number for day of procedure if he or she needs to cancel or has questions for the center (rather than the Navigator).

Navigator Follow-up

- Update notes in data system.

5

Day of Colonoscopy

Call and reach patient or leave voice mail on day of scheduled colonoscopy.

- Obtain information about the patient's experience and any challenges.
- If a voice mail message is left, ask patient to call you when they can.
- Provide information and support if needed, based on the patient's colonoscopy experience.
- Notify Medical Director of any complications reported by the patient.
- Set date of next call and tell the patient to contact you sooner if needed.

Navigator Follow-up

- Update notes in data system.

Preparation for Topic 6

Must be complete before last call to patient.

- Within 2 to 4 weeks after colonoscopy, verify the operative (procedure) report and pathology report (if applicable) are available, and that follow-up recommendations have been established and sent to the patient. If not, resolve through discussion with endoscopist, endoscopy center, or PCP as needed.
- Verify the patient and PCP received the colonoscopy results and recommendations for follow-up. If not, resolve through discussion with endoscopist or his or her office, endoscopy center, or PCP as needed.
- When all information is complete, discuss the patient status with Medical Director on procedure-review call, and record notes in data system.
- If follow-up is needed to address a discrepancy between the recommended interval for screening or surveillance and guidelines, missing information, or lack of a follow-up recommendation, contact the endoscopist office to resolve.

6

Follow-Up and Patient Understanding of Results

Call and reach patient, ideally 2 to 4 weeks after procedure when all of the above are complete.

- Confirm that the patient received and understands the colonoscopy results.
- If the patient has not received results (by letter or phone), work with endoscopy center or provider to send the results and call the patient again to check receipt. (NHCRCS Navigator should never be the one to communicate the results to the patient.)
- Confirm the patient understands when he or she should have a colonoscopy again and affirm the importance of future screening or surveillance colonoscopies. Emphasize the importance of future screening and of screening for other family members if indicated.

Navigator Follow-up

- Update notes in data system.
- Record all calls and plans in data system.
- Ask for feedback about the program.

4

Planning and Implementing a Successful Intervention



In this section

- Getting Started
- Establish the Outcomes
- Select the Patient Population
- Secure Leadership Support
- Hire Staff
- Train Staff
- Develop Partnerships
- Establish the Data System
- Secure Funding and Prepare the Budget
- Develop a Process Manual
- Continue Team Communication
- Implement and Maintain the PN Intervention
- Implementation to Evaluation

"I may be a difficult patient. Although I am compliant with any instructions, I want to know everything. Rarely . . . do all my questions get answered. The glowing exception to this was my Patient Navigator. She was extremely well informed and was gifted in her ability to explain."

NHCRCSP-Navigated Patient

Getting Started

This section addresses planning and implementing the NHCRCSP patient navigation (PN) model in your setting.

Allow adequate time for assessment and planning before the PN intervention start date. The amount of planning time needed depends on your starting point—what is already in place and what pieces need to be secured or built. When you begin navigation, start with a manageable number of patients and increase the number as you gain experience in implementing all aspects of the intervention. It is better to build on early success and avoid being overwhelmed in the beginning. Expect planning and implementation to take a minimum of three to six months from the time you decide to develop or integrate PN for colorectal cancer (CRC) screening into your program or organization.

A. Establish the Outcomes

The foundation for success in using navigation is to articulate clearly the desired outcomes for the PN program (see the [NHCRCSP Patient Navigation Intervention Logic Model in Section 3](#)) and the specific challenges or barriers that must be addressed to achieve those outcomes.

Healthcare system issues can undermine delivery of appropriate patient care, including CRC screening. PN can be helpful in overcoming *healthcare system challenges* to screening and in addressing *individual patient barriers* within a CRC screening program. In any setting, the first step is to identify the intended outcomes and the issues that must be addressed to achieve them.

Using a healthcare system presents challenges for many patients. To make the best use of navigation in overcoming these challenges, your organization must identify the *outcomes* it wishes to achieve through PN. These could include *increasing screening rates, increasing patient satisfaction, or improving efficiency*. You will then need to identify the specific system issues that must be addressed to reach those outcomes. For example, to increase CRC screening rates *within a healthcare system*, you may need to address system issues such as long delays for scheduling a colonoscopy appointment, frequent missed colonoscopy appointments due to ineffective reminder systems, and poor colonoscopy bowel prep due to confusing prep instructions, among other possible system issues. Once you select your intended outcome(s), challenges to achieving those outcomes (such as the challenges listed here) can be identified, and the organization can develop processes, often using navigation, to address those identified challenges.

For CRC screening programs, *achieving desired outcomes requires that you address individual patient barriers*. The NHCRCSP PN model is designed to address those patient barriers to CRC screening and surveillance. Ideally, a *comprehensive CRC screening program* (beyond a PN model) would address both system challenges and individual patient barriers.

The evaluation of the NHCRCSP PN model assessed seven outcome measures (see [Appendix D. The Evidence for the NHCRCSP Patient Navigation Model](#)). As part of planning, gather baseline data for the outcome measures you want to achieve and measure in your evaluation (see [Section 5. Use Data to Maintain a Quality Intervention](#), for details on outcome measures). For example, if one of your outcomes is to increase colonoscopy completion rates among men ages 50 to 75, start by determining the baseline completion rate among this group of men. Or, if a goal is to decrease the rate of missed patient appointments or late cancellations, document the current missed-appointment and late cancellation rates. You can then use those data as a reference point to set your own targets for improvement and to measure your success over time.

B. Select the Patient Population

The patient population you select to receive navigation will be specific to your program or organization. Information about the characteristics of your potential patients may come from statewide screening data captured in a state cancer report, state needs assessment conducted by the health department, or even a previous grant application. If your organization is a health system, use your own system's patient data to assess current CRC screening rates and to identify specific characteristics of those who will receive PN. It is also important to assess the size of the priority population in terms of implementing a PN intervention

Once you have selected your patient population for navigation, base your planning on their characteristics. You may need to partner with a translation service and plan for significant budget resources for this service if English is not the primary language your population speaks and reads. Before beginning implementation, arrange for needed patient resources such as transportation vouchers, phone cards, translation services or other services, if needed by your patient population.

C. Secure Leadership Support

One of the first steps in planning is obtaining leadership support, which can also help you secure organizational funds for the intervention.

Decision makers must understand how the PN intervention will help to achieve the identified outcomes and agree that PN is worth the investment of resources. Securing buy-in will depend on demonstrating that PN is a useful, cost-effective way to increase CRC screening completion and solve challenges such as missed appointments and late cancellations. The NHCRCSP evaluation study results provide a strong argument in favor of this PN model (see [Appendix D: The Evidence for the NHCRCSP Patient Navigation Model](#)). Economic studies also demonstrate that PN can cut costs by reducing missed appointments and late cancellations.^{18, 19}

To communicate the importance and value of navigation, and what you are proposing to leadership, consider developing these helpful tools:

- PN intervention logic model (see [page 8](#)).
- Concise one- to two-page document that makes a case for implementing PN within your organization. Short, bulleted points often work best.

In addition, if you are an endoscopy center or a PCP office, it may be helpful to review the content and timing of the [six-topic protocol](#) with leadership to assess whether the protocol is feasible within your existing system. If you are a stand-alone screening program, obtain the PN Champion and Medical Director's endorsement of the six-topic protocol; their support is essential.

Finally, review the philosophy of shared success and patient empowerment needed for successful navigation with your program's leadership. They should agree on the importance of helping patients to take an active role in their healthcare and ensure that team members understand how to empower patients to accomplish this goal.

Navigation outcomes can help endoscopy centers recover their PN program costs

- Navigation can decrease the number of missed appointments and last-minute cancellations.
- Better bowel prep can result in fewer repeat colonoscopies due to inadequate prep on the initial test.

Missed appointments, last-minute cancellations, and poor preps can cause expensive revenue losses^{18, 19}

D. Hire Staff

As part of your planning, assess staffing needs. Three Core Elements (Core Element 1: Nurse Navigators, Core Element 2: PN Champion with Clinical Expertise, and Core Element 3: Medical Oversight of the Navigation Intervention) directly address staff roles and commitment. Your PN staff could represent a mix of new and existing personnel, depending on your anticipated patient volume. In the NHCRCSP model, the Principal Investigator for the grant program served as the Medical Director (and Champion). In addition to the Navigators, NHCRCSP identified the need for a full-time program director, part-time data coordinator and a part-time administrative assistant. Develop an organizational chart for the PN intervention with percent of time needed for each person. If you are part of a large organization, human resources may support you with hiring activities, including creating job descriptions, recruiting, interviewing, and hiring needed personnel.

Use the following NHCRCSP information to assess how many Navigators you will need:

- On average, Navigators in the NHCRCSP PN model spend about 120 minutes per patient to deliver the six-topic protocol (including time spent on behalf of the patient to reduce barriers). On average, Navigators spend about 80 of those minutes providing direct patient contact over a period of several weeks.
- Experienced full-time Navigators can manage 60 to 100 patients at one time, since only a limited number of patients require direct interaction at any given time. For example, patients are at differing points within their navigation process, and timing between calls at varying points in the process is different. There are longer intervals between planned Navigator-patient contacts after the colonoscopy has been done, and results are pending. And, although certain calls are required at specific times in relation to prep and the colonoscopy date, the timing for other calls (after the colonoscopy) is more flexible.
- NHCRCSP generally limited the number of patients scheduled for a colonoscopy to five to eight patients per full-time employee in a single day.
- Colonoscopy is not appropriate for primary screening in some average-risk patients, such as those with specific health issues. In those situations, the Navigator assists the patient to other resources or alternate forms of screening.

Navigators may work full-time or part-time, but it is essential for them to have dedicated time set aside for navigating their patients. Keep in mind that Navigators may be calling some patients during evening hours when patients are home, and therefore, flexibility in Navigator working hours is important.

Recruiting and hiring the right staff, especially the Navigators, is critically important—these are your team members at the center of the intervention who have daily contact with both patients and partners. The Navigator must be someone who is able to nurture both patient and professional relationships, and who is willing to ask for mentoring or help when needed. This individual must have skills, expertise, and qualities that provide a foundation for becoming skilled Navigators:

- Clinical expertise, including ability to manage complex clinical situations.
- Organizational skills.
- Psychosocial assessment skills.
- Health education expertise.
- Excellent communication skills.
- Ability to learn complex details underlying effective screening.
- Problem-solving skills.
- Consistency and exactness with data and reporting.

- Empathy with patients.
- Flexibility.
- Friendliness and enthusiasm.
- Open-mindedness.
- Passion about making a difference in patients' lives.
- Persistence and diligence.
- Ability to work well with other team members.

Develop the Navigator job description that describes the key responsibilities, education, and expertise that will lead to success in the work. Defining these specifications allows applicants to assess whether the position is truly a good fit for them (see [Appendix H: NHCRCSP Sample Navigator Job Description](#)).

Allow plenty of time for the interview process and consider using behavioral interviewing techniques to gain a clear picture of an applicant's capabilities. This approach to questioning probes applicants about behavior and experiences in a way that predicts potential job success better than traditional interview questions. The interview goal is to get a sense of each candidate as a person, including their attitudes, flexibility, and communication skills, keeping in mind the characteristics needed in a Navigator and for a successful PN intervention.

If you do not already have a **Champion** in place, identify or recruit this individual. The Champion is a healthcare leader who has respect and credibility among the healthcare community and will be a committed advocate in promoting the value of your PN intervention with stakeholders, partners, staff, and patients. Possible Champions may be found among members of your state cancer coalition or local medical and health professional groups.

Medical oversight is a critical component of the navigation model. If your program or organization does not have an experienced provider with significant clinical expertise in endoscopy and CRC screening, you will need to identify someone. One option is to consider a local gastroenterologist committed to CRC screening. This individual needs to be able to provide the peer-to-peer "door-opening" connections to health systems. In addition to consistent medical oversight for the Navigators, he or she must also provide ongoing mentoring of the Navigators, including both clinical teaching and patient communication skills. As with the NHCRCSP model, a single individual may be both the PN Champion and the Medical Advisor, but both roles are essential.

As with the Navigators, develop job descriptions, interview, and hire all other staff identified as necessary.

What is Behavioral Interviewing?

Behavioral interviewing is a technique that asks a job applicant to describe past behavior as an indicator of future performance. For example, "Talk about a time when you helped a patient work through challenges."

NHCRCSP Tip: "Choose someone who has firsthand knowledge of screening and navigation to provide oversight—with a level of experience that can resolve problems—or arrange to have access to someone with clinical expertise in the care you're trying to deliver."
NHCRCSP Medical Director

E. Train Staff

Staff training, both initial and ongoing, lays the foundation for the success of employees and the team. Staff delivering the training should give their undivided attention to the training and have designated time to carry out this responsibility.

Nurse Navigator Training. NHCRCSP developed an eight-week Navigator training program that combined instruction, coaching, and hands-on supervised practice (see [Appendix I: NHCRCSP Patient Navigator Training](#) for a detailed outline). Even if your Navigators have prior experience, training on the six-topic protocol, prep for colonoscopy, and detailed clinical information on CRC screening is important. The Program Director was responsible for the overall training, which included navigation and program processes including use of the data system, and the Medical Director provided clinical training, which included the following:

- An in-depth overview of CRC screening and the compelling case to increase rates.
- Details of colonoscopy including the preparation, and tips for a successful prep.
- Familiarity with common pathology outcomes.
- Guidelines for CRC screening and surveillance.
- Use of sedation and anesthesia.
- Medical issues affecting colonoscopy.
- Cultural issues affecting colonoscopy.
- Other CRC screening tests, assessing patient risk for CRC, and choosing appropriate screening tests.

In addition, training should familiarize Navigators with health insurance options, how to use translation services, and how endoscopy scheduling works in your area. Observing a few colonoscopies is also helpful. The NHCRCSP Navigators received ongoing mentoring, which enhanced the communication and organizational skills that the Navigators brought to their roles.

All Staff Training. Each member of the team should receive training on the larger context of the navigation intervention along with his or her specific responsibilities. The following list presents key training areas for all staff:

- Orientation to your PN program: This is an opportunity to share the mission and vision of providing PN intervention to increase CRC screening. Educate each team member about CRC screening and the difference that high-quality screening can make in patient outcomes. Describe the target population, how the PN intervention works, what to expect, and everyone's role.
- PN intervention: It is important that all team members understand and can explain the benefits of PN. For example, the Administrative Assistant might receive a call from a patient asking why he or she needs to be navigated; the staff member needs sufficient information to answer this type of question.
- PN Process Manual: This manual outlines the PN intervention and processes each team member follows; it is a document used for training and future reference to ensure high quality and consistency. See details for developing a manual on [page 28](#) and a sample outline in [Appendix J: NHCRCSP Sample Process Manual](#)).
- Data system: All members of the team use the data system—the key to intervention monitoring and evaluation—on a daily basis.

Staff **training and development** continue throughout the intervention. These tips will help you support your staff and maximize their potential.

- Consider regular performance reviews for staff so they know what they are doing well and what they can improve. The conversation should be supportive and guide staff to use their individual strengths.
- Take every opportunity to share positive feedback with staff members. Recognize all members of the intervention team for their efforts.
- Provide the administrative support the Navigators need to make their work go smoothly. For example, administrative support personnel should track down reports of prior screening tests, leaving the Navigator to spend time on the clinical patient tasks.
- Find opportunities for professional growth and encourage staff to take advantage of them.
- Mentor Navigators to develop their full potential. If you have chosen good candidates, they come to the position with the right professional background and qualities. They can become outstanding Navigators with the right guidance, education, and opportunities for professional growth.

F. Develop Partnerships

Create a list of the partners needed to make the navigation intervention successful; these relationships may already exist or need to be developed. Consider the scope of your intervention. You may need partners who can work with you to recruit patients or to provide clinical services including PCP visits or colonoscopies.

Endoscopy center capacity may or may not be an issue, and it is important to confirm that the endoscopy centers you will partner with are able to accommodate your patients. The endoscopy center may already be at maximum capacity, especially if the center is small. If so, determine whether they are willing to streamline processes, create efficiencies, or add additional staff to accommodate your patients. It is also important to assess waiting times for colonoscopies to be scheduled, since long delays can create significant barriers to screening.

You also may need to assess available CRC treatment resources. Assess whether your patients often have resources (insurance) to pay for cancer treatment, or whether hospital partners are willing to donate these services or have an uncompensated care program. Colonoscopy screening of average-risk patients will generate only a very small fraction of CRC diagnoses, so treatment costs may not create a large cost burden.

The next step is to engage your partners and agree on the work you will do together. The intervention Champion, Medical Director, or Program Director are likely the staff members who will initially reach out to potential clinical and other partners to build relationships. Decide which individuals should have this responsibility and confirm that they are comfortable reaching out to partners, leaders, and stakeholders. They can use your navigation logic model and business case document to help gain support and participation. Also, when needed, these individuals can help to secure contracts or other formal agreements.

NHCRCS Tip: Navigators play a critical role in nurturing partner relationships and keeping partners committed to the intervention's outcomes. NHCRCS found it helpful for the Navigators to have an onsite desk space at least one day a week in the endoscopy centers serving the largest number of navigated patients. By being onsite, NHCRCS Navigators could maintain relationships through frequent contact with staff, and address avoidable scheduling confusion or delays.

Identifying a primary contact in each partner organization—endoscopy centers, community health centers, cancer centers, and others—is an important part of planning your partnerships. Within the NHCRCSP PN model, some of these individuals functioned as *internal advocates* (or “internal champions” as NHCRCSP referred to them) supporting NHCRCSP’s work from within their individual organizations. These relationships greatly enhanced communication and efficiency with partner organizations, and broadened the reach of NHCRCSP. Establish who the contacts will be for Navigators, data staff, and financial staff, and make contact information readily available.

The Program Director and Navigator can work together to troubleshoot most service-related issues, and the Medical Director or Advisor can resolve issues with endoscopists or centers. However, an ongoing review process is helpful during implementation to make sure that all support services (such as translation services) are fully functional or to add new services as needed. Strong teamwork promotes quick—and when needed—innovative problem resolution.

NHCRCSP tips for sustaining strong partnerships and ensuring patient services:

- Review agreements and contracts annually or as needed to assess how they may need to evolve in response to changing needs. Even if you do not intend to pay for clinical services, your program may need some form of contract with service providers.
- Nurture relationships with partners. As with any relationship, communication is essential, and Navigators may communicate daily with some partners. All interactions should be positive and respectful. Continued engagement of internal advocates promotes your work within individual centers.
- Share accomplishments with partners and recognize them for their contributions. Providing data to let partners know how they have contributed to the intervention will help to keep them engaged. Look for opportunities to acknowledge partners publically among their peers, patients, or other stakeholders. For example, write an article in a professional newsletter or local newspaper.
- Share helpful feedback. Everyone wants to improve. When you can, use data to inform partner feedback.

G. Establish the Data System

Assess data systems available for use. Whether you plan to use something as simple and low-cost as an electronic spreadsheet or purchase a unique data system like the one NHCRCSP used, your system will need certain capabilities including these:

- Ensure patient confidentiality.
- Comply with security requirements.
- Capture and organize the necessary information.
- Search for and retrieve information (patient information, names of patients needing to be called on a given day, notes from previous calls, and test outcomes)
- Produce standard monitoring reports or have the capacity to create custom reports such as number of navigated patients; patient barriers; time spent with patients; topic calls completed; number of patients completing screening; details about the screening such as colonoscopy test results and pathology, if applicable; adequacy of bowel prep; and number of missed appointments or late cancellations.

If you work within an organization, talk with other departments that are tracking data or with your information technology (IT) staff to discuss what system you might use.

As part of developing your data system, you must also determine the data variables needed to support your program, including variables needed to assess the outcomes you are trying to achieve. More information on data variables can be found in [Section 5. Using Data to Maintain a Quality Intervention](#) and in [Appendix E: Patient Navigation Intervention: Suggested Data Variables](#).

Before you launch the intervention, use test data to populate your data variables in mock patient cases in your data system. Once the system has been planned and tested, decide who will enter various data elements into the system and when and how they will do it. You can adjust this process after implementation, but it is essential to start with a defined process and a plan to capture high-quality data. This will allow you to use that information in a meaningful way for monitoring and evaluation. Plan for regular reviews of the data system, including ensuring that all staff have the knowledge necessary to use the system. Every staff member should communicate any data system issues to the staff responsible for data and the rest of the team, and work to support rapid resolution of those issues.

H. Secure Funding and Prepare the Budget

Assess budget and funding resources that are needed for your PN intervention. The budget will come from the staffing assessment (adding in fringe benefits, if applicable), anticipated travel such as partner meetings, supplies, office and patient education material, contracts that might be necessary for data systems and translation services, additional patient resources such as phone cards, and possible assistance with patient transportation. Develop a line item budget using [Appendix K: NHCRCSP Sample Patient Navigation Budget Template](#).

Once the budget is complete, consider how you might fund the intervention if that is not yet established. Potential funding sources are federal grants; private foundations; nonfederal grant support; state health departments; academic, institutional, or medical society grants; and private philanthropy. Navigation within endoscopy centers can often pay for itself through the decrease in missed appointments and last-minute cancellations.^{18, 19} The compelling case for CRC screening in decreasing CRC incidence and morbidity and the proven effectiveness of navigation should be helpful in securing funding.

When funding is confirmed, review the budget for accuracy and determine any additional budget needs. If applicable, engage your finance department to review your budget assumptions and prepare the final draft.

I. Develop a Process Manual

The process manual is a roadmap for a successful PN intervention. It spells out integral processes, describes how you will handle specific situations, and helps personnel understand their roles and responsibilities. Your process manual should describe clearly the purpose of the intervention and how it fits with the values and mission of the organization or program. The process manual also should provide written guidelines for carrying out all aspects of the intervention, including:

- Patient enrollment (see [Appendix L: NHCRCSP Sample Enrollment Process](#)).
- Scheduling processes (referring patients for scheduling, identifying who is responsible for scheduling).
- Prep instructions (mailing instructions to patients).
- The [six-topic protocol](#).

- Processes for how medical information, including past and current reports and pathology reports, will be obtained by Navigators.
- Processes to deal with ineligible patients and those needing treatment.

Based on your planning, you may need to establish processes for contracts, billing and paying for screening services (if part of your program), and reimbursement. See the suggested topics for your process manual in [Appendix J: NHCRCSP Sample Process Manual](#)).

Share your process manual with potential partners during planning. Because your partners will work with you to deliver the full range of services the patient needs, it is helpful for them to understand from the outset how the PN protocol works.

Navigators in this model have the advantage of professional nursing training in setting and maintaining appropriate boundaries with patients. But documenting specific guidelines in the process manual can be helpful for Navigators.

- Establish when navigation starts and ends. Navigation can include following some patients over an extended period of time with occasional check-ins to offer ongoing support as needed.
- Set expectations for what the Navigator will do and what the patient will do.
- Clarify the delivery of support services (for example, if needed, partners will provide transportation or escort the patient home from endoscopy, not the Navigator).
- Establish types of activities that are not appropriate for Navigators, and review these as part of PN training (such as not allowing a homeless patient to stay at a Navigator's home).
- Connect the patient with additional resources at the end of navigation or as needed.
- Finalize the navigation process with encouragement and a congratulatory letter from the Navigators (see [Appendix M: Sample Patient and Partner Thank-You Cards](#)).

J. Continue Team Communication

Ongoing communication with everyone involved in the PN intervention is essential. You should plan and schedule meetings either in person, via Web, or telephone, to build and maintain team communication. The following list describes NHCRCSP meetings:

- **PN Intervention leadership meets weekly** at the start and possibly throughout the intervention to discuss topics related to intervention management.
- **Navigators' supervisor meets weekly with the Navigators** to check in and address any situations needing resolution. This meeting can be used to mentor the Navigators, talk about what is going well with their work, and what needs attention. Navigators also can get advice from one another in dealing with specific patients.
- **Medical Director meets with the Navigators weekly** to review patients with completed procedures, including colonoscopy reports (with pathology if applicable) and endoscopist recommendations for follow-up for each patient. If follow-up recommendations differ from CRC screening and surveillance guidelines, the Medical Director and Navigators develop a plan to address that issue. Navigators call the Medical Director during the week whenever they have questions about medical issues. Regular meetings also include specific mentoring for communication with patients.

- **Team meets monthly** in person to review new clinical or administrative information and to resolve any challenges. These meetings provide an opportunity for team members to share what is going well, to recognize how much the team has accomplished, to discuss information from data reports, and to conduct continuing education and staff development.
- **Team meets in person quarterly** to focus specifically on budget review, administrative issues, data collection and needs, and quality measures.
- **Key partners and Navigators meet biannually** to discuss what is working well and what can improve. Depending on the partner, the Medical Director also might attend.

K. Implement and Maintain the PN Intervention

As you move into implementing the program, complete the following tasks to ensure that your work, relationships, and processes continue to function efficiently and smoothly.

Monitor Spending

Plan and implement quarterly budget reviews. These reviews will compare actual budget expenditures to the projected budget, allowing your program or organization to make adjustments as needed to ensure you are on track with using resources.

Nurture and Maintain Partnerships

Effective partnerships are essential to the success of your program. Continue to nurture and support your partners throughout the intervention.

Continue Staff Development

Ensure regular opportunities for continued staff development to support professional growth.

Review the Data System

Conduct regular reviews of the data system, including ensuring that all staff have the knowledge necessary to use the system. Every staff member should communicate any data system issues to the Data or IT Manager and the rest of the team, and work to support rapid resolution of those issues.

Update the Process Manual

Review and update your manual periodically, assessing what is working well and what needs to be modified. You may need to revise some sections based on experience.

Implementation to Evaluation

As your PN intervention team gains experience, the data captured by the Navigators and other team members become the key to continuous improvement. The final section of the manual will guide you in monitoring and evaluating your PN intervention and using data to make your intervention even stronger.

5

Using Data to Maintain a Quality Intervention



In this section

- Collect Data
- Check Data Quality
- Use Data for Continuous Quality Improvement
- Produce and Review Reports
- Monitor Patient Satisfaction
- Other Important Uses for Your Data
- Conclusion

"To maintain a quality intervention, use your data continuously to monitor implementation and outcomes. The first step is to ensure your data are of high quality."

Dr. Lynn Butterly, NHCRCS Medical Director

A. Collect Data

Collect the data that will allow you to monitor the intervention, evaluate your outcomes, and assess patient satisfaction with the intervention. For instance, to monitor the intervention delivery, you will want to know if the six-topic protocol was implemented, and you will need to collect data on the delivery of each topic. Here is an example of what you might capture for each patient contact.

Example: Call Notes, Topic 6 (Follow-Up and Patient Understanding of Results)

| Date | Topic Type | Mode of Contact | Length of Contact | Follow-Up Date |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------|-----------------|-------------------|----------------|
| 12/16/15 | Follow-Up and Patient Understanding of Results | Phone call | 15 minutes | Not available |
| NOTES: Spoke with patient about his results. His colonoscopy results were normal. We confirmed that he will be screened again in 10 years. Patient will call if he has any more questions. | | | | |

These data and notes recorded by the Navigator make it possible for the team to monitor the navigation process to see if it is being implemented as planned, and to track patient navigation (PN) processes. Without this information, it will be impossible to know whether your team is carrying out the intervention correctly.

You also need to collect data to measure outcomes such as increased screening rates and polypectomies completed. These data help to tell you whether the intervention is a good investment of time and money.

[Appendix E. Patient Navigation Intervention: Suggested Data Variables](#) provides recommended data variables you may wish to collect. You can add more variables specific to your needs. And, as noted in earlier sections, Navigators and other staff will enter these data in your data system throughout your PN intervention.

Some data may not be easily accessible by your organization. If the Navigators do not work for the endoscopy center or you are not paying for the clinical services, you may not have access to some of the data variables from medical records related to bowel prep quality, colonoscopy results, pathology reports, and the recommended screening or surveillance interval. In these situations, you should collaborate with your clinical sites and develop processes to share these data. You will need to address patient consent for releasing medical information.

B. Check Data Quality

Checking the quality of your data is an important periodic task that will take place throughout the life of your PN intervention. Data quality checks assess both the completeness and the accuracy of your data and answer questions like these:

- Does each patient record include all of the required information?
- Are data accurate? That is, do the data accurately reflect patient medical chart content or appointment system content?
- Are Navigators accurately recording their service delivery data, such as patient barriers, patient contacts, time spent serving patients, and relevant patient notes?

Typically, the Data Manager is responsible for conducting periodic data quality checks. The Program Manager also should perform data quality checks monthly or every other week, as needed, for the

intervention, to ensure that Navigators are recording required information in the data system. More frequent checks (at least weekly) would be helpful as the navigation begins.

C. Use Data for Continuous Quality Improvement

Once you are collecting data and are confident the data are high quality, start using the data for program monitoring. Program monitoring involves regularly (monthly) producing and reviewing reports that give you important information about the delivery of your intervention. Regular monitoring is the basis for continuous improvement. For instance, if your data show that patients are not completing their colonoscopies, something is not working. By reviewing data on the number, type, and length of calls made by Navigators to each patient, you may identify potential issues that are contributing to this problem. This type of monitoring can identify problems early, allowing you to make whatever corrections are needed.

Performance measures or indicators are often part of program monitoring. You can create performance measures to monitor both implementation (process) and results (outcomes). It is equally important to monitor both. By monitoring implementation, you can be sure that the PN intervention is being carried out with fidelity (as planned). As we have noted, staying true to the NHCRCSP intervention design will help your intervention achieve positive results.

Below is a summary of process-level performance measures that you can monitor regularly for your PN intervention. The Program Director and Medical Director (or equivalent roles on your intervention team) should monitor these process measures regularly to see if the team is implementing the protocol properly. You also may set benchmarks (targets) for each of the measures. For example, the team might set a benchmark that 80% of patients receive all six topic-specific contacts in the protocol. This may be a challenging target, but it is feasible based on the results of the NHCRCSP evaluation. Assessing this measure (protocol fidelity) will allow you to assess fidelity to the navigation protocol. Monitoring will alert the intervention leaders to quality issues and opportunities to mentor Navigators and improve service. In addition to these quantitative measures, a Program Director may observe the Navigators at work periodically.

Performance Measures–Process*

| Measure | Definition | Numerator | Denominator |
|----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|
| Priority population reach | Priority population is reached effectively for PN (requires a clear definition of the priority population). Example: Priority population is African American men and women aged 50 to 75 who are patients at XYZ health center. | Number of patients assigned to a Navigator meeting priority population definition | Number of patients meeting priority population definition Number of patients assigned to a Navigator |
| Population reach | Proportion of population of screening-eligible patients projected to be navigated who are actually navigated. | Number of screening-eligible patients assigned to a Navigator | Number of screening-eligible patients projected to be served |
| Barrier assessment | Barriers are assessed for patients receiving PN. | Number of patients assigned to a Navigator who had barriers assessed | Number of patients assigned to a Navigator |

| Measure | Definition | Numerator | Denominator |
|------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------|
| Protocol fidelity | Patients receive telephone contacts for all six required topics. | Number of patients who received telephone contacts for all six required topics | Number of patients assigned to a Navigator |
| Time for intervention | Average amount of time (in minutes) per patient that Navigators communicate with patients or act on behalf of patients to facilitate service delivery (recommend collecting time in 5-minute increments; calls must be coded and recorded in record-keeping system). | Total number of minutes Navigators spent delivering the intervention (minutes for all patients navigated combined) | Number of patients who receive navigation services |
| Lost to follow-up | Patients lost to follow-up during the navigation process. | Number of patients the Navigators were unable to reach at some point during navigation and who do not complete a colonoscopy | Number of patients assigned to a Navigator |

*We recommend you assess these measures at least quarterly for monitoring purposes.

The NHCRCSP outcome measures are summarized in the table below, including the actual calculation (numerator and denominator). These measures were assessed as part of the NHCRCSP PN evaluation (see [Appendix D: The Evidence for the NHCRCSP Patient Navigation Model](#)). As with the process measures, you should monitor these outcome measures regularly to ensure you are getting positive results. You also may set benchmarks for each of the measures.

Performance Measures–Outcomes*

| Measure | Definition | Numerator | Denominator |
|-------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|--------------------------------------------------------|
| Colonoscopy completed | Colonoscopy is completed within 12 months of patient receiving confirmation of scheduled test date. | Number of patients with completed colonoscopy within 12 months | Number of patients scheduled for a colonoscopy |
| Adequate bowel preparation quality | Bowel prep is considered adequate (excellent, good, or fair) by the endoscopist performing the colonoscopy exam. | Number of patients with adequate bowel preparation | Number of patients with a <i>performed</i> colonoscopy |
| Missed appointment without prior cancellation | Patient does not cancel in advance of his or her appointment and does not appear for his or her scheduled appointment. | Number of missed colonoscopy appointments without prior cancellation | Number of scheduled colonoscopy appointments |
| Cancellation less than 24 hours prior to appointment | Patient cancels his or her appointment less than 24 hours before the scheduled appointment. | Number of cancellations less than 24 hours before the scheduled colonoscopy appointment | Number of scheduled colonoscopy appointments |

| Measure | Definition | Numerator | Denominator |
|--------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------|--------------------------------------------------------|
| Results communicated to patient | Records indicate that patient received communication about results of the colonoscopy exam. | Number of patients who received screening results | Number of patients with a <i>completed</i> colonoscopy |
| Results communicated to primary care provider | Records indicate that primary care provider received communication about results of the colonoscopy exam. | Number of patients whose primary care provider received screening results | Number of patients with a <i>completed</i> colonoscopy |
| Recommended rescreening interval consistent with guidelines | The number of months or years recommended by the endoscopist before the next colonoscopy is consistent with USPSTF and USMSTF guidelines. | Number of patients with a recommended rescreening interval consistent with USPSTF and USMSTF guidelines | Number of patients with a <i>completed</i> colonoscopy |

*We recommend you assess these measures at least quarterly.

D. Produce and Review Reports

Now it's time to USE those data! Set up periodic stopping points (monthly, for example) when your team will review and discuss the data reports.

Meeting as a team to review the reports is important. Together the team can sort out the meaning of the data and troubleshoot problems, since *all* perspectives are needed for accurate data interpretation. For instance, Navigators are likely to know specific patient or context issues that may explain why performance on a certain indicator looks the way it does.

Over time you will be able to analyze results and identify problem areas you must address to maintain a quality intervention. For example, your data may indicate that patients from a particular endoscopy center have a lower percentage of adequate bowel prep than your desired benchmark. Perhaps the center is prescribing the wrong bowel prep medication or instructions. Recognizing a problem such as this provides an opportunity to address that problem with the endoscopy center and improve quality (for both you and the endoscopy center). Alternatively, sharing strong outcome results with endoscopists or primary care providers will build support for your organization and may contribute to sustainability.

Aside from reports summarizing the process and outcome measures mentioned above, NHCRCSP produced other reports for regular review. Many of these reports addressed ensuring quality care, in addition to monitoring the intervention delivery. You may develop a number of useful reports to support your program. A list of sample data reports follows.

NHCRCSP Sample Data Reports

- **Endoscopy Quality Assurance Report:** For example, percentage of adenomas, average withdrawal time, and other elements of colonoscopy quality.
- **Timeliness of Follow-up Notes Report:** Time (in days) from colonoscopy to last contact for follow-up; a summary of where a patient was in the screening process.
- **Missing Data Report:** A quality report to ensure that all steps (such as consent forms) were completed.
- **Primary Care Provider (PCP) Referrals:** A summary of PCPs who referred patients to the PN intervention (used to thank referral sources and increase referrals).

- **Recommendations:** A means to track screening recommendations for each patient to see if they are consistent with USPSTF and USMSTF recommendations.
- **Weekly Report:** A snapshot of patients served for the current year and their status.
- **Status Breakdown:** A series of reports Navigators use to determine how many patients they had in each phase of the PN protocol. The report helped to manage work load and project when a patient would be due for colonoscopy, or to summarize the complete patient procedure data.
- **Who Is Due?:** A report that tracks when clients will be due for their next colonoscopy.

E. Monitor Patient Satisfaction

By now, you may have noticed the feedback quoted from appreciative patients at the front of some manual sections. NHCRCSP shared these patient quotes from thank-you letters sent to the program and from the patient satisfaction survey. The survey was sent to all patients (see [Appendix N: NHCRCSP Sample Patient Satisfaction Survey](#)). Patient satisfaction surveys are an important feedback resource to enhance program delivery and quality. Using results of the surveys conveys to patients that their input is valuable. You can use patient testimonials with stakeholders—partners, funders, team members, and potential patients—to demonstrate the value of the intervention on a personal basis. The NHCRCSP surveys found that patient satisfaction with the Navigators was high (99.9%)! *Note: Patient satisfaction surveys were distributed in the patient’s primary reading language and were anonymous.*

Other Important Uses for Your Data

Aside from using your data for continuous quality improvement, you can use data to support accountability with stakeholders, including your funders. Share your results in reports to funders, with your organizational leadership, and with other stakeholders (community partners) as appropriate for your program. As you monitor the intervention through regular review of data, you will find opportunities to improve and strengthen your program and your data system. You may create new reports that would help your staff work more efficiently and effectively.

Conclusion

Congratulations! You have completed your review of the NHCRCSP PN replication manual. We hope you have a better understanding of the model, its effectiveness, and how your program can use the model to improve CRC screening.

If you have decided this model is a good fit for your organization and your patient populations, then you are about to begin an exciting journey! Implementing this PN model in the right way will require strong commitment from you, your team, and your organization’s leadership. But it is worth the investment to achieve results—increasing colonoscopy completion rates and ultimately lowering CRC incidence and mortality.

Please contact us at NHPNManual@cdc.gov or NHCRCSP@Hitchcock.org if you have questions, input on this manual, or challenges and successes to share. Thank you for using this replication manual and best of luck with your program!

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Appendices

- A. NHCRCSP Sample Enrollment Form
- B. NHCRCSP Sample Primary Care Provider Colonoscopy Referral Form
- C. NHCRCSP Sample Patient Navigation Welcome Letter
- D. The Evidence for the NHCRCSP PN Model
- E. Patient Navigation Intervention: Suggested Data Variables
- F. NHCRCSP Sample Colonoscopy Preparation Instructions
- G. Colonoscopy Quality Assurance
- H. NHCRCSP Sample Navigator Job Description
- I. NHCRCSP Patient Navigator Training
- J. NHCRCSP Sample Process Manual
- K. NHCRCSP Sample Patient Navigation Budget Template
- L. NHCRCSP Sample Patient Enrollment Process
- M. NHCRCSP Sample Patient and Partner Thank-you Cards
- N. NHCRCSP Sample Patient Satisfaction Survey

Appendix A:

NHCRCSP Sample Enrollment Form

New Hampshire Colorectal Cancer Screening Program (NHCRCSP) Sample Enrollment Form

TO BE COMPLETED BY PATIENT – PLEASE PRINT AND COMPLETE BOTH SIDES

Name: _____ (Last) _____ (First) _____ (MI) _____ (Maiden)
 Date of Birth (Month/Day/Year): ___/___/____ Gender: Male Female
 Address: _____ County of Residence: _____
 City: _____ State: _____ Zip: _____ Phone: (____) _____ - _____
 Other Phone Number: (____) _____ - _____ Email Address: _____
 Can we use this email address to contact you? Yes No Preferred Contact Time? _____
 Mailing Address (if different): _____
 City: _____ State: _____ Zip: _____

NAME OF PERSON IN THE EVENT WE ARE UNABLE TO REACH YOU

Name: _____ Relationship to You: _____
 Phone Number: (____) _____ - _____

DEMOGRAPHIC INFORMATION

Do you have any needs or disabilities of which we should be aware? No Yes, Check all that apply
 Hearing Impairment Speech Impairment Need help making appointments Handicap Access
 Learning Disability Need help filling out forms Other, specify: _____
 Race (Check all that apply): White Black Asian Pacific Islander American Indian or Alaskan
 Unknown
 Are you of Hispanic origin? Yes No
 Primary Language: English Spanish Chinese Korean Other, specify: _____
 Is an interpreter needed? Yes No
 How much is your yearly, household gross income? \$ _____
 Number of people (including yourself) who are supported by this income: _____
 Education (highest level): No High School Some High School High School Graduate or equivalent
 Some college or higher Don't Know Prefer not to answer
 Marital Status: Married Never Married Divorced Widowed Separated Living with someone
 Do you have health insurance? Yes No, if no, are you eligible for Medicaid? Yes No
 If you have health insurance, please tell us what kind: Medicare: Part A Part B Medicaid
 Private Insurance (such as Anthem or Blue Cross) If private, name: _____
 If you have insurance, what is the total amount of your deductible for a colonoscopy? \$ _____

FAMILY HEALTH PROVIDER/DOCTOR

Do you have a primary care provider or family doctor? No Yes, if yes, please complete the following:
 Name of Provider: _____ Name of office or practice: _____
 Phone Number: (____) _____ - _____ Fax: (____) _____ - _____
 Address: _____
 City: _____ State: _____ Month/Year of last visit: ___/___/___

Turn over to complete page 2

Appendix A: NHCRCSF Sample Enrollment Form continued

| CANCER SCREENING HISTORY | |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------|
| Have you had any of the following colorectal cancer screening tests? | |
| Fecal Occult Blood Test (FOBT) or Fecal Immunochemical Test (FIT) in the PAST YEAR? | |
| <input type="checkbox"/> No <input type="checkbox"/> Yes, if yes was your test: <input type="checkbox"/> Positive or <input type="checkbox"/> Negative | |
| Colonoscopy? <input type="checkbox"/> No <input type="checkbox"/> Yes, if yes, please tell us the year of your last test and name of facility where test was done. | |
| Year: _____ | Facility: _____ |
| Were there polyps? <input type="checkbox"/> No <input type="checkbox"/> Don't Know <input type="checkbox"/> Yes | |
| If yes, were you told that any of the polyps were "precancerous"? <input type="checkbox"/> No <input type="checkbox"/> Don't Know <input type="checkbox"/> Yes | |
| Sigmoidoscopy in the last five years? <input type="checkbox"/> No <input type="checkbox"/> Yes, if yes, please tell us the year of your last test and name of facility where test was done. | |
| Year: _____ | Facility: _____ |
| CANCER HISTORY | |
| Have you ever had colon or rectal cancer? <input type="checkbox"/> No <input type="checkbox"/> Yes | |
| Have you ever had other types of cancers? <input type="checkbox"/> No <input type="checkbox"/> Yes, if Yes, type of cancer? _____ | |
| Have any family members had colorectal cancer? <input type="checkbox"/> No <input type="checkbox"/> Don't Know <input type="checkbox"/> Yes | |
| If yes, please list relationship to you and age at diagnosis of the colorectal cancer. | |
| Relationship: _____ | Age at Diagnosis: _____ |
| Relationship: _____ | Age at Diagnosis: _____ |
| Relationship: _____ | Age at Diagnosis: _____ |
| Have any family members had colorectal polyps? <input type="checkbox"/> No <input type="checkbox"/> Don't Know <input type="checkbox"/> Yes, list relationship to you and age found | |
| Relationship: _____ | Age Found: _____ |
| Have any family members had other types of cancer? <input type="checkbox"/> No <input type="checkbox"/> Don't Know <input type="checkbox"/> Yes, if yes, type of cancer(s)? _____ | |
| HAVE YOU EVER HAD OR BEEN TOLD YOU HAVE ANY OF THE FOLLOWING? | |
| Inflammatory Bowel Disease (IBD) (Crohn's Disease or Ulcerative Colitis) | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know |
| Familial Adenomatous Polyposis (FAP) | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know |
| Hereditary Non Polyposis Colorectal Cancer (HNPCC) | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know |
| SIGNIFICANT bleeding from your rectum or bloody stools? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| RECENT NEW diarrhea or constipation lasting more than 2 weeks? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Unexplained weight loss of more than 10% of your body weight? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| MEDICAL HISTORY | |
| Weight (Pounds): _____ | |
| Do you take any blood thinners such as Coumadin or Plavix? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Do you have any bleeding disorders (difficulty getting your blood to clot)? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Are you taking daily prescription pain medications? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Do you use daily supplemental oxygen or a C-Pap Machine? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Are you aware of any problems with sedation or anesthesia? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Do you have any allergies to medications or latex? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| If yes, please tell us what your allergies are: _____ | |
| Do you have a pacemaker or defibrillator device? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Are you a diabetic? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| If yes, do you take any medications for this? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Would you consider yourself in good health? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| If no, please list your medical problems: _____ | |
| Are you a current smoker? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| How did you hear about the program? <input type="checkbox"/> Brochure/Poster <input type="checkbox"/> Mailing (Specify) _____ | |
| <input type="checkbox"/> Healthcare Professional (Specify) _____ | <input type="checkbox"/> Friends / Family |
| <input type="checkbox"/> TV / Radio / Newspaper (Specify name): _____ | <input type="checkbox"/> Other (Specify): _____ |

Appendix B: NHCR CSP Sample Primary Care Provider Colonoscopy Referral Form

(Name/logo of program)

(Program address/phone/fax)

Colonoscopy Referral Form

PATIENT NAME: _____ DATE OF BIRTH: _____

DATE OF LAST VISIT: _____

PROVIDER: _____ OFFICE NUMBER: _____

ADDRESS: _____ FAX NUMBER: _____

INDICATION FOR COLONOSCOPY

- Screening: 50 years or older average age risk
 - No personal or family history of polyps or cancer
- Personal history of polyps. Type: _____
Last colonoscopy date: _____
- Personal history of colorectal cancer*
Last colonoscopy date: _____
- Family history of colorectal cancer*
Relation _____ age of diagnosis _____
Relation _____ age of diagnosis _____

OTHER INDICATORS*

- Personal history of inflammatory bowel disease
- Fecal occult blood positive
- Iron deficiency anemia
- Hematochezia (rectal bleeding)
- Significant gastrointestinal symptoms
Describe _____

*These indications may not be covered by NHCR CSP, but we will help with referrals.

**Prescribing physician should determine whether it is safe to hold anticoagulants and anti-platelets BEFORE this procedure. Please notify NHCR CSP if their medications should not be held.

OTHER MEDICAL HISTORY

- PLEASE ATTACH RECENT HISTORY AND MEDICAL
- Pacemaker or defibrillator
- Recent MI (less than 3 months or unstable angina)
- Insulin-dependent diabetes mellitus
- History of abdominal aortic aneurysm
- History of problems with moderate (conscious) sedation or anesthesia
- Recent chemotherapy
- Require home oxygen continuously
- Allergies (please list):

MEDICATIONS** (see note below)

- Anticoagulation drug (Coumadin, Aggrenox, Lovenox injections) or antiplatelet drugs (Ticlid, Reopro, Integrilin, Aggrastat, Clopidogrel [Plavix])
- Insulin
- Chronic narcotics or pain medication
- Medication list:

This patient is clinically appropriate for outpatient colonoscopy.

Provider signature: _____ Date: _____

Appendix C:

NHCRCSF Sample Patient Navigation Welcome Letter

ORGANIZATION LETTERHEAD

Date

Patient's Name

Address

City, State Zip

Dear Patient's Name,

Thank you for your interest in the New Hampshire Colorectal Cancer Screening Program (NHCRCSF), a statewide effort to increase colorectal screening for NH residents.

We are confirming that NHCRCSF will provide you with "Patient Navigation" services for your upcoming colonoscopy. This means that a NHCRCSF patient navigator will call you a minimum of six times throughout this process to answer any questions you might have about the procedure or the preparation for the test, to assist and support you with any barriers to getting the test, and to make sure you know the results of the test.

If your colonoscopy hasn't been scheduled yet, please call your healthcare provider to assist you in scheduling this important test.

Staff from the doctor's office who will be performing the colonoscopy will call you to give you a prescription for the preparation for the test. If you need this paid for by NHCRCSF, please wait until you have spoken with your NHCRCSF patient navigator before filling the prescription.

Your NHCRCSF patient navigator will call you soon. If you have any questions, please feel free to call INSERT PROGRAM'S PHONE NUMBER.

Sincerely,

New Hampshire Colorectal Cancer Screening Program

Copy to:

NHCRCSF Patient Navigator

Appendix D: The Evidence for the NHCRCSP Patient Navigation Model

Background: Evaluators with the Centers for Disease Control and Prevention (CDC) collaborated with colleagues of the New Hampshire Colorectal Cancer Screening Program (NHCRCSP) to conduct a rigorous evaluation of the patient navigation (PN) intervention. To assess effectiveness, the team used a quasi-experimental research design and compared a subset of 131 patients navigated to a screening or surveillance colonoscopy at one New Hampshire endoscopy clinic to a similar subset of 75 non-navigated, control patients at the same clinic.

Methods: To maximize comparability among the two groups, study participants met five inclusion criteria:

1. Ages 50 to 64 years.
2. Income less than 250% of the federal poverty level, with all patients uninsured and having a source of payment for colonoscopy.
3. Scheduled and notified of the colonoscopy test date between July 1, 2012 and September 30, 2013.
4. Scheduled for a screening or surveillance colonoscopy.
5. No diagnosis of colorectal cancer (CRC) from the completed test.

Because of a small sample size and confidentiality concerns, any records with a diagnosis of cancer were excluded. CDC funds supported clinical services for NHCRCSP-navigated patients and existing uncompensated care programs supported costs for patients in the comparison group. CDC's Institutional Review Board and relevant Dartmouth-Hitchcock committees approved the study protocol.

Evaluators assessed differences between navigated and control patients on seven outcome measures (Table 1). Evaluators computed the prevalence odds ratio to measure the association between PN and the prevalence for each measure.

Table 1. Study Outcome Measures

| Variable | Definition | Numerator | Denominator |
|-------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|--------------------------------------------------------|
| Colonoscopy completed | A colonoscopy is completed within 12 months of patient receiving confirmation of scheduled test date. | Number of patients with completed colonoscopy within 12 months | Number of patients scheduled for a colonoscopy |
| Adequate bowel preparation quality | Bowel prep is considered adequate (excellent, good, or fair) by the endoscopist performing the colonoscopy. | Number of patients with adequate bowel preparation | Number of patients with a <i>performed</i> colonoscopy |
| Missed appointment without prior cancellation | Patient does not cancel in advance of his or her appointment and does not appear for his or her scheduled appointment. | Number of missed appointments without prior cancellation | Number of scheduled colonoscopies |
| Cancellation less than 24 hours prior to appointment | Patient cancels his or her appointment less than 24 hours before the scheduled appointment. | Number of cancellations less than 24 hours before the scheduled appointment | Number of scheduled colonoscopies |

Appendix D: The Evidence for the NHCRCSP Patient Navigation Model continued

| Variable | Definition | Numerator | Denominator |
|-----------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|
| Results communicated to patient | Records indicate that communication was received by patient about results of the colonoscopy exam. | Number of patients who received communication about their results | Number of patients with a <i>completed</i> colonoscopy |
| Results communicated to primary care provider (PCP) | Records show that communication was received by PCP about results of the colonoscopy exam. | Number of patients whose PCP received communication about their results | Number of patients with a <i>completed</i> colonoscopy |
| Final recommended rescreening interval consistent with clinical guidelines | The number of months or years recommended by the endoscopist until the next colonoscopy is consistent with clinical guidelines. | Number of patients who were recommended a screening interval that was consistent with clinical guidelines (for navigated patients, recommendation after possible intervention if needed) | Number of patients with a <i>completed</i> colonoscopy |

Results: The groups were similar in age, family history of CRC, and diabetic status. Over 80% of patients were aged 50 to 59 years in both groups. Despite pre-established inclusion criteria, the intervention (navigated) population included fewer whites (61.1%, as opposed to 77.3%), more females (62.6%, as opposed to 46.7%), and more people who needed a language interpreter (37.4%, as opposed to 10.7%). In addition, a smaller percentage of the intervention group had been screened previously (24.4%, as opposed to 32.0%), had a personal history of CRC or polyps (9.9%, as opposed to 18.7%), or had a smoking history (18.3%, as opposed to 36.0%).

Outcomes for intervention patients were significantly better than controls for all outcomes except communication of screening results to patient, where no difference was detected (Table 2). Specifically, intervention patients completed colonoscopy at a prevalence rate of 96.2% in contrast to 69.3% for control group patients ($p < .001$). In addition, intervention patients had no missed appointments compared to 15.6% for control group patients ($p < .001$). For cancellations less than 24 hours prior to the appointment, intervention patients were nearly 25 times more likely to keep their appointment than control patients.

Table 2. Outcome Results (Proportions, Odds Ratios, p-values)

| Outcome | Intervention Group (n = 131) | Control Group (n = 75) | Intervention versus Control | |
|-----------------------------------------------|---------------------------------|---------------------------|---------------------------------------|----------|
| | Percentage | Percentage | Odds ratio* (95% confidence interval) | p-value† |
| Colonoscopy completed** | 96.2% | 69.3% | 11.2 | < .001 |
| Adequate bowel preparation quality | 97.6% | 87.5%*** | 5.9 | .010 |
| Missed appointment without prior cancellation | 0.0% | 15.6% | 48.4‡ | < .001 |

Appendix D: The Evidence for the NHCRCSP Patient Navigation Model continued

| | Intervention Group (n = 131) | Control Group (n = 75) | Intervention versus Control | |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------|---------------------------|--------------------------------|--------|
| Cancellation less than 24 hours prior to appointment | 0.8% | 16.0% | 24.8 | < .001 |
| Results communicated to patient | 100.0% | 96.2% | 10.1‡ | .084 |
| Results communicated to primary care provider | 100.0% | 48.1% | 272.2‡ | < .001 |
| Final recommended rescreening interval consistent with guidelines | 100.0% | 82.4% | 54.0‡ | < .001 |
| * Unadjusted odds ratios | | | | |
| ** Colonoscopy completed within 12 months of client confirmation of scheduled test. | | | | |
| *** Within the <i>adequate</i> prep groups, navigated patients had a higher relative percentage of good/excellent preps (as opposed to fair preps) than the control group, which had a higher relative percentage of fair preps (as opposed to good or excellent preps). | | | | |
| ‡ Intervention group status predicts perfect success. Odds ratios were computed after adjusting zero cells to 0.5. | | | | |
| † P-values from Fisher's exact tests. | | | | |

Conclusions: These results demonstrate some of the strongest evidence for effectiveness of PN to date, and contribute to a growing literature supporting the value of PN in improving CRC screening completion and related outcomes.

Reference: (submitted for publication)

Appendix E: Patient Navigation Intervention: Suggested Data Variables

PN Variable List

| Variable Name for PN Evaluation | Variable Definition | Comments |
|---------------------------------|----------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|
| Patient ID | Unique patient ID number. | Patients should be assigned a unique ID for tracking purposes. |
| Referral Source | Source of patient referral to the PN program. | Create referral options for your program. |
| Endoscopy Site | Clinic location of provider who performed the colonoscopy. | Create list of provider names for your program. |
| Patient Birth Date | Date of birth. | |
| Gender | Gender of patient. | |
| Race | Self-reported race of patient. | Create additional race variables as needed. |
| Ethnicity | Self-reported ethnicity of patient. | |
| Language | Primary language of patient. | Create list of languages spoken by your patient population. |
| Interpreter | Patient requires interpreter. | |
| Education | Highest degree or level of school completed by patient. | Create appropriate categories. |
| Impairments | Self-reported hearing impaired. | Could have multiple variables to assess various impairments (hearing, speech physical, mental). |
| Scheduling Assistance | Self-reported need for help in making appointments. | |
| Form Assistance | Self-reported need for help in completing forms. | |
| Primary Care Provider | Patient has PCP. | Important to assess whether patient has a PCP and to confirm later that the PCP received test results. |
| PN Assigned | Identify to which Navigator the patient has been assigned. | |
| Verification of Test Date | The date at which the Navigator verbally confirmed with patient that colonoscopy was booked. | Only need one of these dates as either can be selected as the start date for tracking colonoscopy adherence and completion. |
| Notification of Test Date | The date of verbal confirmation between client and clinic that the colonoscopy was booked. | |
| Initial Colonoscopy Test Date | Initial test appointment date. | Could create multiple variables for tracking new test dates when patient cancels or misses an appointment without cancelling. |

Appendix E: Patient Navigation Intervention: Suggested Data Variables continued

| Variable Name for PN Evaluation | Variable Definition | Comments |
|---------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|
| Final Diagnosis | Final diagnosis of the patient. | Create appropriate response categories. |
| Barriers to Screening | Patient barrier to screening. | Would have multiple variable for unique barriers (transportation, language, employer issues, etc.). |
| Reasons Patient Did Not Keep Appointment | Indicates that the patient did not keep his/her appointment. | Create appropriate categories such as no-show/missed appointment, late cancellation within 24 hours of appointment. |
| Date Test Performed | Appointment date for encounter X. If test was performed, this will be the date performed. If no test was performed, a Reason will be indicated and the date will reflect only the scheduled appointment date. | End date for determining colonoscopy adherence and completion. |
| Colonoscopy Outcome | Outcome of performed colonoscopy. | Would have appropriate categories. Used to determine if the colonoscopy was fully completed. |
| Adequate Prep | Bowel preparation was considered adequate by the clinician performing the endoscopy for the colonoscopy exam. | Would be a yes/no response, but consider defining "adequate" based on the scale used by endoscopists (excellent, good, fair). |
| Patient Results | Records show that communication was sent regarding results of the colonoscopy to the patient. | |
| PCP Results | Records show that communication was sent regarding results of the colonoscopy to the PCP. | |
| Recommended Screening or Surveillance Interval | The number of months suggested by the endoscopist before the next colonoscopy occurs. | |
| Guidelines for Screening or Surveillance Interval | The number of months suggested by clinical guidelines before the next colonoscopy occurs. | Will depend on colonoscopy results. |
| Colonoscopy Adherence | First colonoscopy conducted within 6 months. | Computed variable using start date for PN (Verification or Notification of test date) and date first test performed. |
| Timeliness | Number of days between Verification or Notification of test date and date of first performed colonoscopy. | Computed for the first colonoscopy conducted. |

Appendix E: Patient Navigation Intervention: Suggested Data Variables continued

| Variable Name for PN Evaluation | Variable Definition | Comments |
|--------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Completion | Colonoscopy completed within 12 months. | Computed variable using start date for PN (Verification or Notification of test date) and date of completed colonoscopy. |
| No-Show or Missed Appointment | Captures patient no-show or appointments missed without cancelling. | Computed using Reasons Patient Did Not Keep Appointment. You could have multiple variables as patients may miss more than one appointment. |
| Cancellation within 24 hours of Scheduled Appointment | Captures patient cancellation less than 24 hours before appointment. | Computed using Reasons Patient Did Not Keep Appointment. You could have multiple variables for cancellations as patients may cancel more than one appointment. |
| Correct Recommended Screening or Surveillance Interval | Captures consistency of recommended time interval for screening and surveillance exam with clinical guidelines. | Computed by comparing recommended screening or surveillance interval with guidelines for screening or surveillance interval. |
| Time Spent with Patient on Individual Protocol Topics | Time spent on (one of six topics in protocol), including preparation of the call time and data input related to contact. | Could create variables for each of the six topics in the protocol and capture time spent by Navigator in increments of 5 minutes. |
| Total Time Spent with Patient | Total time spent on all 6 protocol topics, including preparation of the call time and data input related to contact. | |
| PN Contacts | Number of PN contacts with patient that are successful (patient reached). | |

Appendix F:

Sample NHCRCSP Colonoscopy Preparation Instructions

Information and Preparation Instructions for Your Colonoscopy

| | |
|---------------------------|--------------------------------------|
| Date of colonoscopy: | Arrival time: |
| Name of colonoscopy site: | Site phone number: |
| Patient navigator's name: | Patient navigator voice mail number: |

A Patient Navigator will guide through the (your program's name) Colorectal Cancer Screening Program. Please review all information before your procedure and talk with your Navigator about any questions or concerns. Your Navigator will call you in the next week and give you his or her name and phone number to write in the top section of this page. The Navigator also will call you before your colonoscopy to make sure you know what to expect and to help you with any challenges. If you need to reach your Navigator you can leave a message on voice mail. Do NOT use the Navigator's number for emergencies.

What is a colonoscopy?

A colonoscopy is a procedure where a specially trained doctor uses a thin, flexible tube with a video sensor on it to look directly at the inside lining of the large intestine, called the colon. The doctor can painlessly remove small growths known as polyps during the test. You should be able to go back to your usual activities the next day.

Are there risks with a colonoscopy?

A colonoscopy is a common procedure and complications are extremely unlikely. But any procedure has some risk. The doctor doing your test will discuss these risks with you. He or she will answer any questions and will ask you to sign a consent form to show that you understand the possible risks.

What to do about your regular medications?

If you take any of the following medicines, please call your doctor to see if it is safe to stop your medications before this procedure (or to take a lower dose of diabetes medication). Your prescribing doctor can give you instructions on how to take your medications before and after your procedure.

- Blood thinners like Coumadin, Plavix, Aggrenox, Lovenox injections, Ticlid, Reopro, Integrillin, or Aggrastat.
- Diabetes medications.
- Prescription pain medications. Please do not stop taking your pain medications before your procedure.
- Iron pills or supplements. Please stop taking one week prior to your procedure.

Appendix F: Sample NHCRCSP Colonoscopy Preparation Instructions continued

Starting **7 DAYS BEFORE** your procedure:

- Arrange for transportation. You will receive sedation (a drug to relax and calm you) during your procedure. You cannot drive for the rest of the day and you **MUST** have a responsible adult to accompany you home. If you do not have someone to escort you home, your procedure will be cancelled and rescheduled.
- Obtain one container of NuLYTELY (or generic PEG-3350, sodium chloride) with the prescription sent to you by the doctor who will be doing your colonoscopy.
- Suggested items to have on hand when you start taking the prep: Flavored drink powder, clear juice such as white grape or apple, clear soda such as ginger ale, popsicles or gelatin dessert (no red, blue, or purple), and broth or bouillon.
- If you have access to the Internet, please visit www.youtube.com/watch?v=xd1N0WOcd5A for a video that provides suggestions related to the prep and colonoscopy.

Starting **1 DAY BEFORE** your procedure:

Start a strict, CLEAR-liquid diet (NO SOLID FOODS). Examples of clear liquids are:

- Apple juice, white grape juice, or white cranberry juice.
- Beef and chicken broth or bouillon.
- Tea or coffee without cream or milk; sugar is acceptable.
- Ginger ale or other clear sodas, water.
- Sports drinks, powdered drinks, gelatin dessert, popsicles.

Do not eat or drink anything red, blue, or purple in color.

Fill the one-gallon plastic bottle that contains the laxative powder (NuLYTELY) with water to the fill line and shake well until the powder is dissolved. ****We suggest you use flavored drink powder instead of the flavor packet you may have received at the pharmacy. Remember, no red, blue, or purple. Flavor each glass and not the entire container, so that you do not get tired of the same flavor. You can refrigerate the gallon or keep it at room temperature. Some people prefer keeping it at room temperature and drinking it through a straw.**

4:00 to 6:00 p.m.—Start drinking the NuLYTELY, with one glass every 10 to 15 minutes if possible. If you feel too full, it is helpful to take a break for 20 to 30 minutes before continuing to drink the preparation. You will drink **half** of this gallon solution the afternoon and evening before your procedure. Refrigerate the remaining half of the solution overnight. On the morning of your procedure, you will drink as much of the **other half** of the solution as you need to **pass clear fluid** when you move your bowels.

10:00 p.m.—You should be passing clear or light yellow fluids when you move your bowels. You should be done drinking half of the cleansing preparation so you can get some sleep. Refrigerate the remaining **half** of the solution overnight.

Appendix F: Sample NHCRCSP Colonoscopy Preparation Instructions continued

Starting **ON THE DAY OF** your procedure:

Drink as many glasses of the prep solution as you need to pass clear or light yellow fluid that morning. This will show you are cleaned out. This may be the entire rest of the gallon that you began drinking yesterday. You must be finished drinking at least two hours before leaving the house. If you are not passing clear or light yellow fluid and you have finished drinking all of the preparation, please call the colonoscopy site (see phone number at the top of page 1) for further instructions before you leave to come to your procedure.

You **MUST** continue on the clear liquid diet the day of the procedure and **STOP** drinking anything two hours prior to leaving the house.

Wear comfortable clothing.

It is important you arrive on time for your procedure (see arrival time at the top of page 1).

Please plan to be at the endoscopy center for about three to four hours for this procedure.

IN CASE OF EMERGENCY, do **NOT** use the phone numbers for the Patient Navigators or the (program name). They only take messages.

*****VERY IMPORTANT*****

If you need to reschedule your appointment,
please give at least 72 hours notice and
call the endoscopy site number on the top of page 1.

Appendix G: Colonoscopy Quality Assurance

Quality Assurance is an essential aspect of colonoscopy, and therefore integral to PN programs for CRC screening and surveillance. There are several quality indicators for colonoscopy. The primary quality indicator is adenoma detection rate, which is the percentage of an endoscopist's screening colonoscopies in which one or more adenomatous (potentially precancerous) polyps are found. Other quality indicators include:

- Quality of prep.
- Withdrawal time (time spent examining the colon during the withdrawal, or inspection phase of the exam).
- Percentage of colonoscopies complete to the cecum (innermost reach).

Periodic monitoring of these and other quality indicators for your patients' exams will add to quality assurance for the intervention. The References list includes two sources that explain colonoscopy quality indicators.^{1,2}

Appendix G: References

¹Schoenfeld PS, Cohen J. Quality indicators for colorectal cancer screening for colonoscopy. *Techniques in Gastrointestinal Endoscopy* 2013;15(2);59–68.

²Anderson JC, Butterly LF. Colonoscopy: Quality indicators. *Clinical Translational Gastroenterology* 2015;6:e77.

Appendix H:

NHCRCSP Sample Navigator Job Description

Patient Navigator

JOB SUMMARY: An integral part of the intervention, the Navigator reports to the Program Director and reviews all patients and any medical or endoscopic issues with the Medical Director of the intervention. The Navigator's primary function is to guide colonoscopy patients through the healthcare system, assisting them with access and negotiating any barriers to a successful colonoscopy. This includes ensuring appropriate follow-up and understanding of all aspects of the screening process. Navigators will develop relationships with providers and their office staff, conduct internal and external outreach, contribute to efficiency for gastrointestinal practices, and track outcomes of the intervention.

Responsibilities:

1. Manage and guide patients from enrollment through delivery of all medical care and appropriate follow-up.
2. Complete data entry for each patient as defined by the protocol.
3. Identify and develop relationships with personnel in departments involved in patient care. Offer educational sessions to inform personnel of the PN role and program services to encourage referrals.
4. Identify resources in the community for transportation and primary care visits.
5. Provide colonoscopy education to patients and groups and provide materials in several languages as appropriate.
6. Ensure that patients enrolled in the program have a recent (within one year) visit with a primary care provider and, if not, facilitate the health check. Communicate with the Medical Director and endoscopy sites if medical conditions exist that may require attention prior to or during colonoscopy.
7. Ensure that referrals, procedures, communication, and follow-up occur in a timely fashion as outlined by the policies and procedures.
8. Collaborate with the Program Director and Medical Director to develop and implement program policies and procedures.
9. Build relationships with other Patient Navigators and community healthcare workers.
10. Perform other duties as required or assigned.

MINIMUM EDUCATION AND EXPERIENCE: Must be a registered nurse with at least three years of experience in oncology, endoscopy, or community health. Must have excellent communication skills and work effectively in a team. Strong computer skills preferred.

Appendix I: NHCRCSF Patient Navigator Training

This model is based on use within an organization. In addition to organizational elements, it contains the elements needed for a PN program.

| Week 1: General Orientation and NHCRCSF Overview | |
|--------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Organization | <ul style="list-style-type: none"> • Human resource policies. • Occupational health. • Recording work, holiday, and vacation time. • HIPAA and confidentiality. |
| Department | <ul style="list-style-type: none"> • Office tour and keys. • Job description. • Organization chart. • Staff roles. • Confidentiality. • Safety checklist. • Culture of the department. • Staff development and required learning. • Department-specific expectations for the first 90 days. • Office supplies. • Mail. |
| Computer and documents | <ul style="list-style-type: none"> • Computer setup and passwords. • Accessing drives remotely. • PDF software. • Drives. • Calendar, word processing, and spreadsheet training. • Folders and files. • Printer, copier, scanner, and fax machines. • Database overview. |
| Phone Training | <ul style="list-style-type: none"> • Cell phone use and voice mail. • Language line training. |
| CDC Overview | <ul style="list-style-type: none"> • <i>Screen for Life</i> materials. • CDC cancer Web site (www.cdc.gov/cancer/). • Patient information handouts. • Navigators observe colonoscopies. |

Appendix I: NHCRCSP Patient Navigator Training continued

| | |
|-----------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Overview of Policies and Procedures</p> | <ul style="list-style-type: none"> • Process Manual. • Intake through test process. <ul style="list-style-type: none"> – Intake line. – Primary care provider form and notes. – Data entry. – Satisfaction surveys. • Endoscopy sites. <ul style="list-style-type: none"> – Contracting partners and maintaining relationships. – Internal advocate in contracting organizations. • Program services (translation, transportation, escort). • Six-topic protocol (PN minimum requirements). <ul style="list-style-type: none"> – Navigation techniques. – Tricks for successful bowel prep. • Data entry and data system. • Follow-up Items for next week. |
| <p>Week 2: Resources and Observation</p> | |
| <p>CRC Screening</p> | <ul style="list-style-type: none"> • Comprehensive overview of CRC screening and surveillance, including details of screening tests and patient risk assessment. • Full review of guidelines (USPSTF and MSPSTF). • Basic pathology overview. • Observe full day of colonoscopy. |
| <p>Observation</p> | <ul style="list-style-type: none"> • Navigator trainee observes experienced Navigator conducting calls. |
| <p>Review</p> | <ul style="list-style-type: none"> • Resources and locations where available. • Endoscopy site contacts and processes. • Brochures and Web sites. • Language line. • Data system and data entry. • PN minimum requirements. • Symptom review document. • CDC’s guide to health literacy. • Follow-up items for Week 3 training. |
| <p>Week 3: Observation of Navigator or Program Director and Medical Director</p> | |
| <p>Shadowing and Observation</p> | <ul style="list-style-type: none"> • Navigator trainee observes an experienced Navigator or Program Director and Medical Director in all aspects of role (data system, contacting endoscopy sites). • Observes patient review call with Medical Director and experienced Navigator (review of procedure variables and pathology for patients with completed colonoscopies). • Reviews patients for next week’s calls. • Review follow-up items from Week 2 and list for next week. |

Appendix I: NHCRCSP Patient Navigator Training continued

Week 4: Supervised Practice

- Navigator trainee begins making patient calls with experienced Navigator observing and intervening.
- Ongoing feedback to trainee.
- Trainee observes a pathology call.
- Review follow-up items from Week 3 and list for next week.

Week 5: Independent Mentoring

- Navigator begins making calls with experienced Navigator observing, but not intervening.
- Ongoing feedback to Navigator.
- Participates in a pathology call.
- Review follow-up items from Week 4 and list for next week.

Week 6: Relationship Building

- Continues to make calls with an experienced Navigator observing.
- Visits and meets with staff of endoscopy sites to begin to build relationships.
- Participates in a patient review call.
- Review follow-up items from Week 5 and list for next week.

Week 7: Continued Mentoring

- If ready, the Navigator trainee begins to make calls without an experienced Navigator, but the trainee notifies an experienced Navigator when call and data are complete for immediate review.
- If not ready, the Navigator trainee continues with independent mentoring.
- Navigator trainee observes Administrative Assistant on intake line.
- Review follow-up items from past week and list for next week.

Week 8: Independent Navigator Assumes Caseload

- Navigator trainee has ongoing daily meetings with an experienced Navigator.
- Review follow-up items from past week and list for next week.
- Navigator mentoring and medical oversight continues throughout the intervention.

Appendix J:

NHCRCSP Sample Process Manual

Process Manual Outline

- I. Intervention Overview
 - Overview of why CRC screening is important
 - Brief background of the PN intervention
 - Goals and intended outcomes for the PN intervention
 - PN logic model
 - Important stakeholders
 - Important partnerships for your PN intervention
- II. Quality Assurance
 - Patient confidentiality
 - Colonoscopy quality assurance
 - Openness to diverse cultures
 - Endoscopy sites and quality assurance
- III. Recruitment and Enrollment for PN
 - Strategies for in-reach and outreach to recruit patients
 - Patient eligibility criteria for PN
 - Patient enrollment processes and who is responsible
 - Assignment of patients to Navigators
- IV. PN Delivery
 - Description of the content and rationale of the PN protocol
 - Facilitating services to overcome assessed patient barriers
 - Maintaining partner relations
 - Quality assurance and mentoring meetings
- V. Referral and Scheduling Process
 - Steps in referral and scheduling and who is responsible
- VI. Data and Reporting
 - Procedures for reviewing and reporting data on navigation service delivery
 - Procedure for obtaining, reviewing, and reporting patient-related data
 - Monitoring reports and frequency of review
 - Data quality checks
- VII. Billing and Payments (If your organization will pay bills for colonoscopies, you may wish to work with your finance personnel in creating this section.)

Appendix K: NHCR CSP Sample Patient Navigation Budget Template

| BUDGET TEMPLATE PROGRAM (NAME) BUDGET FOR (YEAR) | | | | | | |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------|-----------------------------------|------------------|----------------------|----------|------------------|
| PERSONNEL | | | | | | |
| Position Title and Name | Annual Salary | Percent of full-time employee | Number of Months | Total | In-kind | Total |
| Medical Director | | | | | | |
| Program Director | | | | | | |
| Data Coordinator | | | | | | |
| Data Entry or Administrative Assistant | | | | | | |
| Patient Navigators | | | | | | |
| FRINGE BENEFITS – Fringe benefits are usually applicable to direct salaries and wages and are usually a rate. | | | | | | |
| Total amount of salaries multiplied by fringe benefit rate | | | | | | |
| TOTAL TRAVEL – Project which staff will need to travel to meetings with partners and endoscopy sites and calculate the cost of the travel; usually based on the IRS mileage allowance. | | | | | | |
| Position Title | Number of staff | Number of trips | Number of miles | Cost per mile | Subtotal | Total |
| Medical Director | | | | | | |
| Program Director | | | | | | |
| Data Coordinator | | | | | | |
| Data Entry or Administrative Assistant | | | | | | |
| Patient Navigators | | | | | | |
| Conference Travel (Name) | Number of staff | Number of nights | Unit Cost | | Subtotal | Total |
| Registration and Membership | | | | | | |
| Flights | | | | | | |
| Hotel | | | | | | |
| Parking and Transportation | | | | | | |
| Meals | | | | | | |
| Total for Trip | | | | | | |
| EQUIPMENT – Check with your finance department, as there is usually a minimum amount for an item to be considered equipment versus supplies. Equipment could be a computer, copier. | | | | | | |
| Item requested | Number Needed | Unit Cost | | | | Amount requested |
| SUPPLIES – Consider office supplies, postage, educational materials, translation services, copier use, and printing. | | | | | | |
| Item requested | Type | Number needed or number per month | Number of Months | Unit or Monthly Cost | | Amount requested |
| CONSULTANT COSTS – Includes hiring of an individual to give professional advice or services, such as training. | | | | | | |
| CONTRACTUAL COSTS – Includes contracts such as language translation services and cost of CRC screenings. | | | | | | |
| OTHER – This includes items not listed in other budget categories. | | | | | | |
| INDIRECT AND ADMINISTRATIVE CHARGES – May include rent, lights, and other expenses. | | | | | | |
| TOTALS | | | | | | |

Appendix L: NHCRCSF Sample Enrollment Process

Patients came to NHCRCSF primarily by self-referral or referral from a primary care provider (PCP) or another program. Enrollment in the PN intervention included these steps:

1. A program staff person conducted patient intake by telephone, entering patient's information (name, address, contact information, PCP name) into the NHCRCSF database. A staff person mailed the patient an enrollment packet that included:
 - Information on PN.
 - CDC educational brochures on colorectal cancer (CRC) and colonoscopy.
 - Consent form for participation.
 - Enrollment form for patient to provide their medical history (see [Appendix A: NHCRCSF Sample Enrollment Form](#) and [Appendix C: NHCRCSF Sample Patient Navigation Welcome Letter](#)).
 - Authorization form for the use and disclosure of protected health information (allows the PCP and endoscopist to release patient information to NHCRCSF) for the patient to sign and return with the consent and enrollment forms.
2. The program required a PCP visit within the last year for each patient. The PCPs filled out and signed a referral form detailing the patient's medical history and physical to confirm that the patient was medically cleared and appropriate for outpatient endoscopy (see [Appendix B: NHCRCSF Sample Primary Care Provider Colonoscopy Referral Form](#)).
3. The Administrative Assistant obtained previous CRC screening test results and pathology reports to ensure the patient was due for screening or surveillance. NHCRCSF staff entered all patient information into the data system.
4. The Program Director, with support from the Medical Director, made the enrollment eligibility decision and assigned patients to a contracted endoscopy center in the patient's area and to the NHCRCSF Navigator who worked with patients using that endoscopy center.
5. Navigators guided patients who were ineligible for the program (due to medical reasons) to other resources.

Appendix M: NHCRCSF Sample Patient and Partner Thank-You Cards

Patient Thank-You Card



(Inside of Card)

Congratulations on taking care of yourself by having your colorectal cancer screening!

New Hampshire Colorectal Cancer Screening Program

Appendix M: NHCRCSP Sample Patient and Partner Thank-You Cards continued

Partner Thanksgiving Card



(Inside of Card)

At this time of Thanksgiving celebration,
Our thoughts turn gratefully to you
With warm appreciation.

Thank you for contributing to the health of your community.
The New Hampshire Colorectal Cancer Screening Program
(staff signed each card)

Appendix N: NHCR CSP Sample Patient Satisfaction Survey

Thank you for being part of the Patient Navigation (PN) program. To help us improve the program, please complete this survey and mail it back to us in the enclosed envelope.

Please circle "Yes," "No," or "Unsure" for each statement. If your answer is "No," please explain in the comments column. Your comments will help us serve you better in the future. Your comments will not affect your participation in the PN program.

Name of facility or hospital where your test was performed: _____

| | Response | | | Comments |
|----------------------------------------------------------------------------------------------------------------------------|-----------------|----|--------|-------------------------|
| Intake staff were helpful and courteous. | Yes | No | Unsure | _____ _____ _____ |
| My Patient Navigator (nurse who called me several times) explained the colonoscopy so that I could understand the test. | Yes | No | Unsure | _____ _____ _____ |
| My Patient Navigator explained the instructions for drinking the prep for the colonoscopy so that I could understand them. | Yes | No | Unsure | _____ _____ _____ |
| The staff at the colonoscopy facility or hospital were helpful and courteous. | Yes | No | Unsure | _____ _____ _____ |
| I would recommend this program to a friend or family member. | Yes | No | Unsure | _____ _____ _____ |
| All of my questions were answered. | Yes | No | Unsure | _____ _____ _____ |

Please list your ideas or additional comments to make our Patient Navigation program better.

Thank you for your help and prompt response!