

Links of Care:

Report on a Pilot Project to Increase Colorectal Cancer Screening Rates and Ensure Access to Specialty Care for Underserved Patients

Pilot Project: 2015-2017

Report: 2019



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Executive Summary

Colorectal cancer (CRC) screening can prevent cancer, but many adults are not getting recommended testing. Federally Qualified Health Centers (FQHCs) provide care for many uninsured and Medicaid patients, but struggle to obtain access to specialty care for patients when needed. The *Links of Care* pilot project (2015-2017) implemented evidence-based strategies to increase screening rates and timely access to specialists after abnormal screenings in three FQHCs. A process and outcome evaluation was conducted using twenty-four key informant interviews and quarterly monitoring reports. FQHCs successfully increased CRC screening rates by 8-28 percentage points, secured low- or no-cost colonoscopies from specialty care providers, and implemented patient navigation to ensure timely follow-up to diagnostic services. Key facilitators included buy-in from key stakeholders, a strong navigation program, stool-based first-line testing, and support from a neutral convener. By engaging partners and implementing internal processes improvements, FQHCs can increase CRC screening rates and enhance access to follow-up.

Acronym Guide

ACS: American Cancer Society

CDC: Centers for Disease Control and Prevention

CRC: Colorectal cancer

CMO: Chief Medical Officer

FQHC: Federally Qualified Health Center

GI: Gastroenterology

HRSA: Health Resources and Services Administration

NCCRT: National Colorectal Cancer Roundtable

UDS: Uniform Data System

Background

Colorectal cancer (CRC) is the second leading cause of cancer death in the U.S., with an estimated 140,000 adults diagnosed each year. With screening, CRC can be detected when treatment is most likely to be successful, and in many cases CRC can be prevented by removing precancerous polyps. About 1 in 3 adults aged 50 or older—approximately 23 million people—are not getting tested as recommended.¹ This problem disproportionately affects underserved populations, as evidenced by CRC screening, incidence, and mortality rates.²

Federally Qualified Health Centers (FQHCs), the medical home for nearly 26 million people in medically underserved communities,³⁻⁴ are uniquely positioned to address screening disparities. In 2012, the Health Resources and Services Administration (HRSA), required their funded health centers to report CRC screening rates as a standard performance measure through the Uniform Data System (UDS). The interest in CRC screening spurred by this requirement created an opportunity to improve CRC screening rates in the FQHC setting.⁵

While colonoscopy is the most common method for CRC screening, many FQHCs screen for CRC with stool-based tests. If positive, however, these tests still require follow-up colonoscopy and treatment in a timely manner in order to reduce mortality.⁶ Access to either screening or follow-up colonoscopies is an acute problem for many FQHC patients.⁵ Colonoscopies typically occur in hospitals, endoscopy suites, or ambulatory care centers, thus there is an interest in building stronger relationships between FQHCs and specialty providers in the “medical neighborhood” (i.e., the array of clinicians a patient may see as they seek care)⁷ to reduce access barriers to the full continuum of care in the delivery of CRC screening.

For these reasons, when the National Colorectal Cancer Roundtable (NCCRT), a coalition co-founded and co-supported by the American

Cancer Society (ACS) and the Centers for Disease Control and Prevention (CDC), launched a public health goal to regularly screen 80% of adults aged 50 or older for CRC, the strategic plan included a key objective to make tests, such as colonoscopy, affordable and accessible to everyone who needs them.⁸ Under the leadership of then-US Assistant Secretary for Health Dr. Howard Koh, the ACS and NCCRT joined with CDC, the National Association of Community Health Centers, the American College of Gastroenterology, and other agencies and professional societies to examine several community-level programs that had successfully addressed the challenge of delivering CRC screening and follow-up for FQHC patients.⁹⁻¹⁰ Model programs had several commonalities: one or more physician champions; an understanding of the number of colonoscopies needed; strong patient navigation/care coordination systems; support from a neutral party to help partners convene and negotiate; and a “fair share” model amongst colonoscopy providers.

Drawing on the lessons-learned from the model programs, in 2014 ACS and NCCRT launched the *Links of Care* pilot project to build specialty care linkages for FQHC patients in need of CRC screening and follow-up. Pilots were launched in three communities and focused on two strategies to provide greater access to CRC screening and needed follow-up and treatment for uninsured and under-insured patients:

1. Medical Neighborhood Strategy: Support medical neighborhood development by securing no- or low-cost colonoscopies and other services from hospital systems, endoscopy and surgical services providers.
2. Screening Navigation Strategy: Improve CRC screening processes by implementing or strengthening screening navigation to ensure eligible patients receive a CRC screening recommendation and are navigated through screening and follow-up.

Regional ACS staff identified FQHCs with capacity and interest and invited them to submit proposals. Pilot sites were selected through a competitive process conducted by an internal ACS team. Applicants committed to (1) developing the long-term structures and relationships needed to improve linkages for the delivery of CRC screening, including increasing timely access to specialists for either screening or follow-up colonoscopy and (2) advancing evidence-based strategies to increase CRC screening rates within their FQHC.

Three FQHCs were selected: Westside Community Health Center (now called Minnesota Community Care) in St. Paul, MN (urban), Fair Haven Community Health Care in New Haven, CT (urban), and Beaufort Jasper Hampton Comprehensive Health Services, Inc. in Port Royal/Lowcountry, SC (rural). The pilots received support through funding and technical assistance provided by model programs experts and ACS staff. ACS staff also organized community assessments, and initial stakeholder meetings for each pilot.

In this paper, we present evaluation findings from the *Links of Care* pilot, including the process of establishing the medical neighborhood, implementation of the screening navigation component, and an overview of the critical program components and facilitators and barriers to implementation.

Methods

The overall objective of the *Links of Care* evaluation was to assess the extent to which pilot sites successfully implemented the strategies, as well as facilitators and barriers to implementation and service delivery. The evaluation, which was deemed a non-research activity by the Morehouse School of Medicine Internal Review Board, assessed program process and outcomes both qualitatively and quantitatively, as described below.

Qualitative Methods and Analysis

Evaluation site visits were conducted in July-August 2016 to collect data about program implementation, medical neighborhood partnerships, and internal practice changes including patient navigation. Site visits included in-depth, semi-structured interviews with purposively selected key informants from FQHCs, specialty partners, and ACS regional staff. Interview guides were similar across participants but tailored to each participant's role on the project. Three evaluators conducted 24 interviews total, with two evaluators participating in each site visit. Interviews lasted between 30-60 minutes and were recorded and transcribed with participant permission. The three evaluators created a deductive codebook using concepts of interest from the interview guides (i.e., initiation, medical neighborhood, navigation, ACS role, sustainability, facilitators, barriers). The evaluation team conducted two rounds of intercoder agreement checks before dividing up the remaining transcripts to code individually using MAXQDA.

Quantitative Methods and Analysis

Pilot sites submitted quarterly reports with aggregate data on the number of stool tests returned, colonoscopies (follow-up or screening) referred and completed, as well as other reporting measures. Sites also reported their annual system-wide CRC screening rates to UDS. These data are publicly available on the HRSA website.

Results

The three pilot sites successfully established a strong medical neighborhood and screening navigation program. They ultimately overcame numerous challenges to successfully implement individualized CRC screening programs in collaboration with medical neighborhood partners. While the focus of the evaluation of the pilot was on process and implementation, we observed that each site experienced increases in stool tests, colonoscopies and screening rates over time. In what follows, we outline key

components of implementing each strategy, along with other critical facilitators and barriers to implementation.

Implementing the Medical Neighborhood Strategy

Each FQHC established partnerships with at least two specialty care providers, including private gastroenterology (GI) practices, hospitals, and surgeons. Two of the three FQHCs used their partnerships with specialists for colonoscopies after positive stool tests. The third began the pilot referring all patients for screening colonoscopies, but over time transitioned to stool tests first with follow-up screening as needed. The following are components that led to successful implementation of the medical neighborhood strategy.

Accessing Key Decision-makers

The pilots had to identify and access specialty care providers in order to build the medical neighborhood. Where available, the personal networks of key stakeholders were useful in forming partnerships. The CEO of one of the participating FQHCs was a GI with extensive relationships to other local GIs and a personal history of providing donated care, which facilitated access to the GI community to make an appeal. The other FQHCs relied on ACS and other local public health programs to help build connections to specialty care providers.

Beyond identifying and contacting specialty care providers, it was important to gain access to key decision-makers within their health systems to move the project forward. Two FQHCs were able to bring key health system decision-makers to the table for an introductory meeting and secure their commitment to participate during that meeting. The third FQHC began the project working with an enthusiastic provider, but when this practice was acquired by a large hospital group, the FQHC was unable to meet with leadership to persuade them to continue participating. It took months for this FQHC to identify a new partner because they were unable

to access the right decision-makers and make their case to leadership, secure commitments and continue progress.

Making an Effective Appeal

When approaching potential partners to provide donated colonoscopies, leaders from both the FQHCs and specialty partners identified two key components to making an effective appeal: the humanitarian case and the business case. The humanitarian case focused on the motivation to help others and appealed to the potential partner's sense of compassion and/or social justice. Participants described several ways they did this: emphasize the responsibility to care for the underserved; highlight challenges in access-to-care for the patient population; point out the importance of prevention as a form of patient care; humanize the problem through sharing patient stories; and appeal to the altruistic spirit that brought many health care providers to practice medicine in the first place.

The goal of the business case was for the FQHC to delineate the parameters of the partnership by providing information on the estimated number of colonoscopies needed each month, thus defining a clear and manageable commitment of low cost or donated care (e.g., one colonoscopy a week or month). When attempting to partner with safety net hospitals, participants also recommended emphasizing the likely cost savings to be had by donating preventative care: *"That person who is out there that doesn't have a primary care doc or insurance, five years from now when they start losing weight and start bleeding and show up in our ER, and now we admit them, and now they have advanced cancer and don't have resources and we keep them, we're paying for that. So there is a cost avoidance part that you could figure in"* (hospital CMO).

The business case also addressed concerns about the patient population by promoting navigation processes. FQHC staff perceived that specialists assume FQHC patients would be more problematic than insured, higher income

patients (e.g., more likely to no-show show up for scheduled appointments or show up poorly prepped). This project employed patient navigators to ensure that patients maximized low cost or donated colonoscopy appointments (described below). Those FQHCs with prior patient navigation experience included data on no-show rates and patient preparation in the business case to persuade potential partners.

One hospital chief medical officer (CMO) described the humanitarian and the business case this way: *“My first question: Is it a better way to take care of patients? Yes. The second question has to be: Is it going to break the bank? If it is, then [...] we don’t necessarily abandon it, but we think, okay is there a better way we can do it. [...] And then the third part is: Is it something that is going to [overwhelm] our docs?”* However, the relative importance of the humanitarian case versus the business case varied based on organizational characteristics of the potential partner specialty care providers. FQHCs had an easier time persuading specialty care providers to participate when they were employee-owned, where leaders and providers are one-in-the-same. Partnerships were more difficult to establish with specialty practices owned by large hospital organizations—particularly when key decision-makers are located outside the community. In these instances, participants shared that the humanitarian case was less effective and increased emphasis and detail was needed in the business case.

Building the Medical Neighborhood

Once FQHCs secured partnerships with specialty practices, they had to develop effective referral and communication processes with partners to truly build a medical neighborhood. Participants from both FQHCs and specialty partners found joint, regular meetings helpful to address problems in real time, as well as identifying a point of contact to handle communication with medical neighborhood partners. In most cases, these points of contacts were patient navigators at the FQHC and referral coordinators at the

specialty care system. Good communication systems between partners were also necessary to resolve patient billing issues when they occurred and ensure colonoscopy results were communicated back to FQHCs.

Interestingly, once initial partnerships with specialty care providers were established, this helped beget more partners and further build the medical neighborhood. Having specialists in the area who had already agreed to provide low cost or donated care made it easier to get buy-in from new partners because the perceived burden was lower when it was shared across many providers. In some cases, specialists actively helped recruit additional partners. An FQHC COO described how partners can aid with recruitment this way: *“[Partner hospital] said we need some more folks to put some skin in the game. We’re taking on these patients. [...] And they even said that to [other specialty practice] and said, ‘Hey, put some skin in the game. What are you doing about these positives [tests]?’”* In instances where ancillary services such as anesthesiology or pathology were under distinct leadership from the specialty partner, partnering providers took the initiative to secure those services either by asking ancillary service providers to donate the care or by covering those costs themselves as part of the specialty partner’s donation.

Implementing the Screening Navigation Strategy

FQHCs worked with ACS regional staff and model program experts to develop their internal FQHC screening navigation programs (or modify their existing programs).

Navigation Training and Troubleshooting

ACS provided training and guidance for building a navigation program to increase CRC screening. An FQHC site visit from model program experts also helped trouble shoot workflow. FQHCs adjusted existing workflows, trained staff on CRC screening referrals, and brought in educational materials. FQHCs defined navigator roles based

on a range of inputs including prior experience with similar models, literature on patient navigation, and clinic practices/protocols. The process was iterative, as one navigator noted: *“We had meeting after meeting after meeting after meeting. [The Chief Nursing Officer] and I met almost every day trying to figure out policies, procedures, protocols, how are we going to go about doing this? Who is going to do this? That was daily for quite a while, in between everything else.”*

For FQHCs that did not have an existing navigator program, it took approximately three months for FQHCs to get their navigation programs up and running. One FQHC experienced delays stemming from changes in specialty partners, and another struggled to fill the navigator position due to the temporary nature of grant funded hiring.

Navigator Qualities

Each FQHC selected a navigator familiar with community needs either because they were already working at the FQHC or because they were members of the community themselves. Beyond community familiarity, other key qualities that enabled navigator success included speaking multiple languages, passion for helping others, comprehensive grasp of resources available to address barriers, being an independent worker and problem solver, and dedication and commitment to helping patients access cancer screenings. One navigator noted the importance of such skills given the autonomous nature of the position: *“It’s a very independent job as well. You can easily slack. So you have to be like a real go-getter and you really care about your patients and you have passion for this program...because...nobody will know if you called [your patients] or not.”*

Patient Education

Navigators were intended to increase the number of patients who completed CRC screening, including follow-up colonoscopies after positive stool test, by assisting patients

throughout the process. The navigator role often began during primary care appointments. Navigators were sometimes brought into the examination room to educate patients about screening processes and to provide reluctant patients with reassurance that they would guide them through the process. They also assisted with language and cultural barriers to CRC screening. A clinic navigator stated, *“some of these fears is that they’re afraid that they actually find something [e.g., polyp, cancer] and they don’t want to know.”* In these situations, navigators worked to put patients at ease by offering alternate screening options (e.g., stool tests instead of colonoscopy), and by informing them that finding abnormalities early increases treatment options and can positively impact prognosis. At one FQHC, the navigator pre-scanned providers’ schedules to identify eligible patients and proactively sought out those patients to educate them about CRC screening. Any patients the navigator could not meet with in person was contacted by phone afterward.

Ensuring Good Preparation and Show Rates

When patients were referred for screening or follow-up colonoscopy, navigators managed the referral process and interacted at multiple touch points with patients and medical neighborhood partners to ensure good preparation and show rates. Navigators helped patients obtain screening preparation kits and provided detailed instructions on how to prepare for colonoscopy appointments. One navigator had an open-door policy for helping patients prepare: *“I pretty much tell them to come in whenever you’re free because I don’t want to set an appointment and then have them not show up. [...] And then I give them the prep information in Spanish and in English if they speak English. I print out like the picture of the medicine that they have to go buy. And I go through everything with them.”* Another FQHC required all patients attend a scheduled face-to-face meeting with the navigator before their appointment, and if patients did not appear for this meeting the navigator would cancel the colonoscopy and schedule another patient in their place. This protocol enabled the navigator

to maintain a very low no-show rate, which protected the relationship with the specialists donating no- or low- cost care. Other support navigators provided included delivering colonoscopy prep materials to patients and physically drawing time indicators on prep bottles to help patients successfully complete colonoscopy prep.

Navigators also served as liaisons between patients and specialists during scheduling to ensure patients were given appointments that worked with their schedules, while addressing other patient barriers that could prohibit patients from completing CRC screenings. For transportation barriers, navigators helped eligible patients acquire free rides through the Medicaid program or they contacted family members or friends to assist patients with rides to colonoscopy appointments.

Implementing Tracking and Reminder Systems

Finally, navigators were responsible for managing a tracking system for stool tests and screening and follow-up colonoscopies. Tracking methods were primarily electronic, but navigators stated that they keep separate Excel files for tracking patients to minimize errors experienced using EHR systems. For stool testing, navigators sent reminders if kits were not returned by patients. For colonoscopy appointments, navigators tracked attendance and followed-up with patients who did not appear. While navigators did not typically play a major role in the care continuum for those patients who required additional follow-up and/or treatment after colonoscopy, they did continue to track patients through the continuum and would assist specialty providers as-needed in reaching patients to encourage them to adhere to recommended treatment plans.

Facilitators

In addition to specific medical neighborhood and navigation facilitators already described, we identified several facilitators important to overall program success.

Leadership Support

All FQHCs reported previously conducting CRC screening to varying extents; however, this pilot was distinct from previous attempts because of the heightened degree of involvement and support from FQHC clinical and administrative leaders who prioritized CRC screening. FQHC CEOs at all sites strongly supported the project and ensured adequate staffing and resources for implementation. All FQHCs noted the importance of maintaining leadership involvement and staff buy-in throughout the project. Two FQHCs identified sharing data with staff as an effective way to achieve buy-in by demonstrating project progress and success. One CMO who was initially skeptical of the project became one of its strongest proponents after seeing early successes. According to another FQHC administrator, *“Everyone likes to hear when they’re making progress and you’re doing something good.”*

Neutral Support and Trouble shooting

All pilots reported the importance of having ACS local health systems staff play the role of neutral convener. ACS health systems staff organized initial stakeholder meetings at all three sites and worked with FQHCs to identify and invite crucial partners. At meetings, stakeholders reviewed the results of community assessments, heard from model program experts, and created action plans. The meeting also included representation from ACS and NCCRT leaders who enhanced the legitimacy of the project and demonstrated national support for the work. In most cases, FQHC staff reported the meeting fostered medical neighborhood partnerships, as noted by an FQHC leader who described the meeting as *“essential” for “getting the potential partners in the room and getting buy-in about what the numbers [of needed colonoscopies] are.”* Beyond

this initial meeting, ACS health systems staff provided regular guidance and assisted with trouble-shooting, often serving as a sounding board to negotiate challenges and keep the projects moving forward.

Ongoing FQHC Staff Engagement

All FQHCs conducted ongoing staff trainings to promote practice changes. A particularly impactful training involved an ACS expert clinician reviewing the literature on the value of stool-based testing with FQHC staff, which generated buy-in from some providers who initially preferred colonoscopy and were reluctant to use stool-based tests. As one CMO stated, *“Many of the people that work in our health centers, that was their training. You do colonoscopy, or you don’t do anything at all because you’re going to miss it [cancer] anyway. It [the training] really made the case...for [stool-based] screening. And it was compelling, and people then researched it on their own and found exactly the same data.”*

Barriers

We also identified several common barriers that the pilots needed to overcome.

Initial Hesitation

Participants noted some FQHC primary care providers were reluctant to refer because they did not trust that no- or low-cost care would materialize—particularly if they had negative partnership experiences in the past. One FQHC CMO said: *“We got a lot of negative feedback from our provider group. We weren’t getting buy-in because [...] there’s nothing more uncomfortable as a practitioner to be sitting in a room when you have a treatable illness and a high-risk person, and you can’t do anything about it.”* The challenge is not to convince primary care providers that screening is important, but rather to build the trust that specialty partners are committed and will provide the needed care.

Billing Challenges

The most common challenge reported in working with medical neighborhood partners related to billing. Every partnership reported some instances where patients received bills that they were not supposed to, either from GIs or for ancillary service providers. FQHC staff reported telling patients to reach out to them immediately if that occurred, and they worked directly with the specialty care practices to take care of the bills, but these instances still caused undue stress for patients. Some of the processes to address this included taking steps to ensure that patients were correctly identified as recipients of low cost or donated care, modifying previously used “flat rate” packages that were developed for use with employers, or applying strategies that specialty care providers had used previously for large scale donated care.

Practice Stipulations

One practice also put requirements in place that made it more difficult for FQHCs and their patients to obtain colonoscopies, including requirements that patients speak English, have Medicaid, or come at specific times of day or the month. For FQHCs with multiple screening partners, the presence of such barriers lead to backlogs for those facilities that were more accommodating while referral slots went unfilled at other locations.

Colonoscopy as First-line Screening

As described previously, one practice began with a colonoscopy-based program, in which colonoscopy was the primary CRC screening method and stool tests were recommended to patients who refused colonoscopy. While the practice was able to secure additional colonoscopies for their patients, the volume of patients simultaneously increased, making it hard for the practice to progress in terms of increasing CRC screening rates overall. For this reason, the practice transitioned over time to a program in which stool tests were offered first with colonoscopies reserved for follow-up to positive tests as needed.

Program Outcomes

All sites experienced a substantial increase in the number of stool tests completed (Table 1). While

we do not have the denominator to allow us to calculate the stool test return rate, the data indicates increased use of the stool test in each pilot site.

Table 1. Number Stool Tests Completed

	2014	2015	2016	2017
Site 1 (stool-based program)	123	415	1,188	1,229
Site 2 (stool-based program)	141	374	1,395	1,055
Site 3 (colonoscopy-based program)*	28	57	69	182

*Program transitioned to stool-based in the later years of the program

The number of both screening and follow-up colonoscopies performed increased across all sites (Table 2), with the greatest increases occurring in later years of the project. This demonstrates the FQHCs' ability to secure and effectively utilize donated, low-cost

colonoscopies from specialty partners, particularly when used as a follow up to positive first line screening exams. In some instances, anesthesiology and pathology services were donated as well, however these donations were not tracked as part of program data.

Table 2. Colonoscopies Performed (Screening and Follow-up)

	2014	2015	2016	2017
Site 1 (stool-based program)	4	18	27	87
Site 2 (stool-based program)	13	11	33	100
Site 3 (colonoscopy-based program)*	103	239	143	259

*Program transitioned to stool-based in the later years of the program

While the pilot's day-to-day work focused on implementation, the ultimate goals were to increase CRC screening and follow-up care. System-wide screening rates increased over the course of the pilot, with greater increases in later years (Table 3). This table also includes provisional screening rates for the year following the conclusion of the pilot, which demonstrates

the varying ability of the FQHCs to continue their progress after the end of the grant. While this window goes beyond our evaluation, it is interesting that the progress that began with the *Links of Care* pilots continued in two of the three pilot sites, with CRC screening rates in one program surpassing the 80% goal, while one pilot site regressed.

Table 3. Colorectal Cancer Screening Rates

	2014	2015	2016	2017	2018
Site 1 (stool-based program)	25%	38%	44%	39%	36%
Site 2 (stool-based program)	38%	38%	55%	66%	87%
Site 3 (colonoscopy-based program)*	44%	44%	50%	52%	59%

*Program transitioned to stool-based in the later years of the program

Discussion

The *Links of Care* pilot program was successfully implemented in three sites that varied in geographic location, patient population, and available external resources. All FQHCs successfully overcame many challenges to engage external specialty partners to secure a finite number of low- and no-cost colonoscopies and implemented or strengthened highly effective screening navigation programs. Key factors for successful implementation included support from a neutral public health partner (ACS) and FQHC leaders, stakeholder meetings that enabled partners to convene and develop a shared vision, implementation of a navigation program, and continued staff engagement to support the project. Pilot participants from both FQHCs and specialty care practices noted the interdependent nature of the two *Links of Care strategies*, emphasizing critical importance of patient navigation in establishing and maintaining mutually beneficial medical neighborhood relationships.

Although funding support for the pilot has now ended, all FQHCs and specialty partners expressed initial intent to sustain and expand the processes and collaborative relationships

developed through the pilot by exploring partnerships with additional specialty care providers and expanding to additional clinic sites within the FQHC systems. Sites also expressed interest in identifying longer-term policy solutions to circumvent the lack of FQHC operating funds to support the crucial screening navigator role, such as securing funding for this role through state dollars or through Medicaid reimbursement. As 2018 screening rates show, two pilot programs successfully continued to advance their efforts while one did not. An important follow up analysis should be conducted to understand what factors drove these differing outcomes.

To further support increased CRC screening rates, ACS is developing a web-based *Links of Care* implementation program based on lessons learned from this pilot. The program model will be disseminated widely to provide guidance on how to accelerate the process of building medical neighborhood partnerships and implementing navigation programs to facilitate CRC screening and follow-up care for FQHC patients, and ultimately, to prevent avoidable death from this disease.

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