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Patient Navigation in a Colorectal Cancer Screening Program

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Abstract

Context—Colorectal cancer (CRC) is the second leading cause of cancer death among cancers affecting both men and women in the United States. The Centers for Disease Control and Prevention’s Colorectal Cancer Control Program (CRCCP) supports both direct clinical screening services (screening provision) and activities to promote screening at the population level (screening promotion).

Objective—The purpose of this study was to characterize patient navigation (PN) programs for screening provision and promotion for the first 1 to 2 years of program funding.

Participants—We conducted a cross-sectional survey of the 29 CRCCP grantees (25 states and 4 tribal organizations) and 14 in-depth interviews to assess program implementation.

Main Outcome Measures—The survey and interview guide collected information on CRC screening provision and promotion activities and PN, including the structure of the PN program, characteristics of the navigators, funding mechanism, and navigators’ activities.

Results—Twenty-four of 28 CRCCP grantees of the survey used PN for screening provision whereas 18 grantees used navigation for screening promotion. Navigators were often trained in nursing or public health. Navigation activities were similar for both screening provision and promotion, and common tasks included assessing and responding to patient barriers to screening, providing patient education, and scheduling appointments. For screening provision, activities centered on making reminder calls, educating patients on bowel preparation for colonoscopies, and tracking patients for completion of the tests. Navigation may influence screening quality by improving patients’ bowel preparation for colonoscopies.

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The authors have no conflicts of interest to report.

Conclusions—Our study provides insights into PN across a federally funded CRC program. Results suggest that PN activities may be instrumental in recruiting people into cancer screening and ensuring completed screening and follow-up.

Keywords

colorectal cancer neoplasms; early detection of cancer; health promotion; patient navigation; uninsured

In 2009, a total of 142 664 new cases of colorectal cancer (CRC) and 26 806 deaths were reported.¹ Colorectal cancer screening tests detect cancer early, resulting in better treatment outcomes and, through endoscopy, prevent cancer by detecting and removing precancerous polyps. Nevertheless, only 39% of CRCs were diagnosed at an early stage² and only 65% of adults were up to date with CRC screening in 2012,³ a significantly lower proportion than the *Healthy People 2020* target of 70.5%.⁴ The US Preventive Services Task Force recommends screening for CRC using fecal occult blood testing (FOBT) annually, sigmoidoscopy every 5 years combined with FOBT every 3 years, or colonoscopy every 10 years in adults, starting at 50 years of age until 75 years.⁵

Low-income, uninsured or underinsured, racial/ ethnic minority, and non-English-speaking populations experience CRC-related health disparities and have lower rates of screening.³ Individual barriers to screening include mistrust of the health care system, lack of knowledge, fear of pain, and fatalistic attitudes about cancer.^{6,7} Structural or systems barriers include lack of insurance coverage, provider recommendation, transportation, and interpreters.⁶⁻⁹ Barriers exist related to specific tests include resistance to handling stool or confusion about doing the test correctly (FOBT) and fear of sedation and complications (colonoscopy).¹⁰ Patient navigation (PN) has emerged as an important approach to reduce cancer disparities by addressing barriers to cancer care.¹¹⁻¹³ General characteristics of PN include the following: (1) assisting patients to identify and overcome barriers; (2) providing support and facilitating patients' access to clinical services; and (3) for cancer screening, ensuring adherence to screening guidelines, reducing the number of patients lost to follow-up, and improving timeliness of diagnosis and treatment.¹² There is limited published research on the effectiveness of PN for CRC screening. A small number of studies have been conducted, and several have significant limitations (eg, small sample size, no comparison group).^{11,12} However, some recent studies with more rigorous study designs have evaluated the effectiveness of PN in increasing CRC screening and found PN effective in addressing individual and system barriers to CRC screening faced by low-income, underserved populations,¹⁴⁻¹⁶ improving screening quality, as well as follow-up and diagnostic care, for patients with abnormalities.^{17,18} Specific to CRC screening, few studies provide descriptive information on the types of activities provided by patient navigators and their background and training. In addition, while the Community Preventive Services Task Force recommends a number of strategies to increase CRC screening, including client reminders, small media, one-on-one education, reducing structural barriers, provider assessment and feedback, and provider reminders, the task force has not conducted a systematic review of PN.¹⁹ These are critical areas to understand, given the current national

focus on health promotion and outreach initiatives to increase CRC screening to 80% by 2018.²⁰

The Centers for Disease Control and Prevention (CDC) implemented the Colorectal Cancer Control Program (CRCCP) in 2009 with the goal of increasing CRC screening rates to 80% in funded states/tribes/tribal organizations by the end of 2014. The 29 grantees (25 states and 4 tribal organizations) receive CRCCP funding to (1) provide direct CRC screening to low-income, uninsured, and underinsured adults (referred to as screening provision) and (2) implement interventions to increase screening rates at the population level, with an emphasis on the use of evidence-based strategies (referred to as screening promotion).²¹ Grantees typically implement programs statewide (or tribe-wide). About half of the CRCCP grantees offer colonoscopy, and half offer fecal testing (abnormal fecal tests are followed by colonoscopy). The CDC requires that up to one-third of CRCCP funds support screening provision with the remaining two-thirds allocated for implementation of screening promotion activities. As part of the screening provision component, PN may be offered to patients for whom screening is paid by the CRCCP. For screening promotion, grantee staff or partners may provide PN to patients whose screening is paid for by sources other than the CRCCP (eg, insurance, Medicare).

Assessing PN use in the CRCCP, including detailed information about the navigators and the activities they perform, may help identify factors contributing to implementation effectiveness and provide information for improving PN efforts in the future. The purpose of this study was to characterize PN programs in supporting screening provision and screening promotion in the first 1 to 2 years of the CRCCP. Clinical and cost data as well as select qualitative data that reflect PN service delivery (eg, training, evaluation) are also reported. These data provide further insight into the use and potential impact of PN and therefore are an important complement to the grantee survey data.

Methods and Materials

This study was conducted by members of the Cancer Prevention and Control Research Network, a national network of academic, public health, and community partners who work together to reduce the burden of cancer, especially among those disproportionately affected.²² The CDC and the National Cancer Institute fund the Cancer Prevention and Control Research Network to accelerate the adoption of evidence-based cancer prevention and control practices.

A Cancer Prevention and Control Research Network workgroup developed and implemented a survey and qualitative study as part of CDC's CRCCP evaluation. Twenty-nine CRCCP grantees were asked about the first 2 years of program implementation in a cross-sectional, online survey collected from November to December 2011. Program directors of the CRCCP identified the person most knowledgeable about the program's daily operations to complete the survey. The qualitative study involved interviews with program directors or coordinators from 14 of the grantees about their navigation activities in the past year and occurred from March to October 2013. We used a purposive sampling of half of the grantees because of time and resource constraints; the sample was chosen to represent

different entities (ie, state vs tribal organization) and evidence-based interventions (EBIs) used (ie, high vs low implementers). The study protocol was reviewed and designated as exempt by the University of Washington institutional review board. The qualitative study protocol was also designated as exempt by the Emory University institutional review board.

Within the survey, 7 topics were covered: CRCCP integration with other CDC-funded programs, CRC screening provision, CRC screening promotion, access of CRC screening data from nonprovision sources, CRC screening policies and strategies, training and technical assistance for EBIs, and general program management. We included questions about the use of PN for screening provision (navigators supporting patients screened by the CRCCP) and promotion (navigators supporting patients not screened by the CRCCP), characteristics of navigators, including background and education, navigators' service delivery activities, and payment mechanisms for navigation services (eg, staff time, per patient reimbursement). Data were entered in Qualtrics (Qualtrics, Provo, Utah) and then analyzed in SPSS 19 (IBM, Armonk, New York). We performed descriptive analyses to better understand the use of PN and navigator characteristics and activities. We described PN activities for screening provision and promotion. We used the number of grantees using PN (n = 18) as the denominator for screening promotion. Patients navigated as part of screening promotion receive different test types.

For the qualitative study, the interview guide addressed 5 areas including the screening promotion activities, delivery of EBIs, PN, systems changes, and desire for technical assistance on program delivery and skills on how to use evidence-based strategies. The interview was digitally recorded and transcribed verbatim. NVivo 10 software (QSR International, Burlington, Massachusetts) was used for data storage, retrieval, and analysis. A detailed codebook was developed, and 2 independent coders coded each transcript.

In addition, clinical and cost data, which reflect PN efforts reported to the CDC by 26 grantees that initiated screening within the first 2 years, were summarized. As a requirement for CRCCP funding, a minimum set of clinical data are collected on all patients screened with CRCCP funds and reported to the CDC semiannually. We analyzed the first 2 years of screening data to assess screening outcomes potentially affected by navigation efforts. Cost data are collected and reported to the CDC annually and include both CRCCP funding from the CDC and financial resources secured from other sources that support the program. Year 2 PN costs data were reported.

Results

Twenty-eight grantees completed the survey, including 23 state health departments, 4 tribal organizations, and 1 health system (response rate = 96.5%). Some grantee programs operate statewide, whereas others are regional. Grantees typically have contracts with health systems or clinics, health departments, and community-based organizations to conduct screening provision and promotion activities. The respondents were mostly program directors (32%) or managers (43%), and 68% had been involved in the CRCCP between 1 to 3 years (data not shown). More grantees reported using navigators to support patients screened by the CRCCP (n = 24) than to support patients who were not screened by the CRCCP (n = 18)

(Table 1). A majority of grantees reported that the navigators in their programs had professional training with either a nursing or public health background. For CRCCP screening promotion, navigators were more often professionals than lay health workers.

The number of patient navigators involved in grantee programs varied, and navigators were financially supported in different ways. The most common approach to funding navigation services for screening provision was the use of grantee staff as navigators (33%), followed by staff support to providers for navigators or per patient reimbursement for navigation services (29% each). For screening promotion, grantees more often provided staff support for navigators to providers (39%) by offering funds for full-time equivalents, followed by the use of grantee staff as navigators, per patient reimbursement, or other methods (22% each). Overall, grantees paying directly for navigators reported having a mean of 4.63 (SD = 2.7) fulltime equivalent navigators or case managers for screening provision and 5.69 (SD = 2.8) full-time equivalent navigators for promotion. On average, navigators were placed at 5 different provider sites each for provision and promotion.

Grantees reported on a series of activities conducted by their navigators (Table 2). Overall, their navigators involved in screening provision conducted similar tasks to their navigators used in promotion. The most common activities nonspecific to a type of screening test included assessing patients' barriers to screening (96% provision, 94% promotion), educating patients about CRC screening modalities (100% provision, 94% promotion), and scheduling screening appointments (83% for both provision and promotion). In comparing navigator activities between screening provision and promotion, navigators for screening provision more often arranged for dependent care (38% vs 28%) and assisted patients with cancer with access to treatment (92% vs 72%). However, navigators who worked to promote screening more often conducted patient recruitment (89% vs 71%).

Specific to screening provision, grantees using colonoscopy as the primary test (n = 12) reported that their navigators made reminder calls for colonoscopy appointments and for bowel preparation (both 92%), assisted patients in accessing bowel preparation materials (83%), tracked patients to ensure the procedure was performed (92%), and made follow-up calls after the colonoscopy to check on patients (83%). A little over half of the 12 grantees reported that the navigators (58%) met patients at their endoscopy appointment. All grantees using FOBT as the primary test (n = 11) reported that the navigators tracked patients to ensure the receipt of the kits and made reminder calls to return the kits (100%). For screening promotion, grantees reported navigators as having made reminder calls for colonoscopy appointments (83%) and assisted patients in accessing bowel preparation materials (83%). Only 56% of grantees reported that navigators made reminder calls to encourage patients to return FOBT or fecal immunochemical test (FIT) tests, although this may reflect fewer programs working with FOBT/FIT testing.

With regard to the number of persons navigated for screening promotion, about 44% of grantees reported navigators working with a total of 101 to 500 patients during the past year whereas 33% reported seeing 501 to 1000 patients (Table 3). Seventeen grantees reported collaborating with partners (n = 17); many (61%) partnered with 1 to 5 organizations for PN services and either led or coled (65%) the activities. For example, several grantees partnered

with federally qualified health centers (FQHCs) for navigation services to reach patients in multiple counties whereas others worked with private health care systems or through cancer coalitions. The primary partners of grantees for PN for promotion were either FQHCs or local health departments.

Other aspects of the impact of CRCCP PN efforts are based on analysis of cost and clinical data collected. Cost data collected for the CRCCP indicate that, during year 2, PN comprised 11% of total screening provision costs and 17% of total screening promotion costs.²⁰ On the basis of clinical data collected on patients screened with CDC funds during the first 2 program years, for initial screening tests (ie, FOBT, FIT, sigmoidoscopy) requiring diagnostic colonoscopy, 78.3% (596/761) completed diagnosis, and of those, 72.8% were completed within 90 days (n = 14). For all colonoscopies, including screening and diagnostic, bowel preparation quality was adequate for 98.1% (total n = 8099 colonoscopies). For patients who had their cancers diagnosed, 97.5% (n = 39/40) started treatment and 92.3% started treatment within 60 days.

From the qualitative interviews with select grantees, more detailed information about training of the navigators and evaluation metrics was described. We found that training of navigators varied from grantee-led training to standardized, formal training programs (eg, Harold Freeman Institute, American Cancer Society). Some navigator training programs were intensive, involving multiple-day trainings with online modules in between, and covered public health, importance of cancer screening, roles of navigators, and insurance options. Some grantees required that navigators participate in online or other courses to maintain certifications received after their initial training. A few grantees had navigators participate in community health worker training programs for acquisition of basic skills.

In terms of evaluation, some of the interviewed sites reported using metrics for PN. These evaluation indicators included the percentage of patients not coming in for a scheduled colonoscopy (no show rate), the percentage of patients with adequate bowel preparation, and the percentage of patients completing screening (adherence rate). Two sites used a customized PN data system or module to track patients and record client contacts, including PN services performed. Some grantees expressed an interest to collect qualitative feedback from patients and satisfaction data.

Discussion

Our results add to a growing literature on PN used for cancer screening. Specifically, our findings provide insight into characteristics of navigators engaged in a large-scale, federally funded CRC screening program. At the 2-year mark, we found that 24 of the 28 CRCCP grantees completing the survey were using PN for screening provision and 18 grantees used PN for screening promotion. Three grantees had not initiated screening at the time of the survey. The fact that fewer grantees are supporting PN for screening promotion may reflect CDC's emphasis on the use of evidence-based practices¹⁹ or challenges in partnering with health systems for PN. In general, however, data collected by the CDC²³ suggest that PN accounts for 17% of total screening promotion and 11% of screening provision costs.

We also found that, in contrast to models of PN that primarily rely on lay health workers, CRCCP navigators often had a professional background in either nursing or public health with associate, nursing, or college degrees.¹¹ This may also explain why, for the screening provision component, only 75% of the grantees relied on navigators who had experience working with the priority population, a characteristic typical of lay health workers. For screening promotion efforts, even fewer grantees (67%) involved navigators with this experience. Grantees may have elected to use professional patient navigators due to the clinical complexity of CRC screening and the range of services delivered by navigators. Training of the navigators varied, with some grantees requiring participation in intensive, formal programs and others using community health worker training or certification programs.

The range of activities performed by navigators supported in the CRCCP is consistent with what has been reported elsewhere.^{24–30} To our knowledge, this study is one of the first to report on the extent of PN activities performed for endoscopic versus fecal CRC tests, such as reminders for bowel preparation for colonoscopies or calls about receipt of FOBT kits. The high percentage of grantees supporting navigators who are conducting tracking and follow-up activities for both FOBT and colonoscopy is promising, given that these efforts are critical to supporting screening and diagnostic test adherence. Of interest, navigators from 11 of 12 grantees (92%) reporting colonoscopies as their primary test tracked patients through colonoscopy screening. Continued and improved patient tracking will be essential to supporting screening and rescreening adherence. Furthermore, core elements of PN should be explored. Elements of PN interventions may have been included in past systematic reviews of strategies to increase cancer screening such as reducing structural barriers.³¹ However, PN has not been identified and recommended as a separate “strategy” for assessment by the Community Guide for Preventive Services, and it may be that it involves multiple components such as one-on-one education, small media, and reducing structural barriers.

Of particular interest, we found that navigators were more often engaged in patient recruitment for screening promotion than provision, often partnering with local health departments and FQHCs, agencies largely serving disenfranchised populations. As the Patient Protection and Affordable Care Act³² (ACA) is implemented, navigators and community health workers may play an important role in helping newly insured individuals enter and negotiate the health care system to receive preventive services, including cancer screening. Studies have shown that access to health care alone is not adequate to ensure screening compliance.^{33,34}

Clinical data collected on those screened with CDC funds suggest that navigators may be contributing, in part, to high-quality bowel preparation and, for those with a diagnosis of cancer, treatment initiation, although improvements related to completeness and timeliness of diagnostic colonoscopies are indicated. As a whole, the CRCCP was falling short of the established target of 80% for completing diagnostic colonoscopies within 90 days during the first 2 years. Performance for this indicator is, in part, influenced by contextual factors outside grantees' control (eg, wait times for colonoscopy appointments, patients' schedules); however, expanded and/or strengthened navigation may improve this metric in the future.

On the basis of the most recent clinical data available, the CDC reports that this indicator is now being met.

Among those interviewed, grantee-led evaluation of PN varied, although 2 were using formalized PN data systems. As the CRCCP evolves, adherence data, process, and intermediate outcomes for PN such as the percentage of patients assessed for barriers, appointment cancellation and no-show rates, and satisfaction with navigation services may be collected.³⁵ The existing PN programs for CRC have focused their evaluation on patients navigated,¹⁴ timeliness to definitive diagnosis,^{17,18} screenings completed,^{15,16} patient satisfaction,¹⁶ trust in the PN,¹⁶ and program costs.¹⁴ We recommend in future PN evaluations to include not only clinical outcomes (ie, screening adherence, timeliness of diagnosis) but also patient-reported outcome measures such as satisfaction, self-management or health behaviors, and quality of life.³⁵ The CDC has produced reports to facilitate networking across grantees related to PN and other evidence-based strategies and regularly conducts training webinars for grantees, including trainings addressing PN. Rigorous evaluation studies of specific PN programs within and outside the CRCCP are needed to assess the effectiveness of unique models (eg, centralized telephonic model, patient reimbursement model) that serve differing populations (eg, rural, unique racial/ethnic groups) with low screening rates. Our results suggest that there are different models of PN at work within the CRCCP, especially with regard to where navigators are physically placed (eg, FQHCs, public health agencies, endoscopy sites). The CDC has one such evaluation underway, examining a centralized model whereby 2 nurses provide navigation telephonically to patients screened for colonoscopy across a largely rural state. More in-depth exploration of navigator approaches to patient tracking and monitoring may also be warranted to understand how these processes may contribute to screening adherence. Finally, core metrics for monitoring PN are being defined that will inform program improvements and allow for performance comparisons across grantees.^{36,37}

This study has several limitations. First, survey and interview data were cross-sectional and reflect the perspective of program directors and coordinators. In addition, a single grantee may support navigators working in multiple clinics; therefore, implementation may vary across sites within that grantee program. More in-depth information may be obtained directly from navigators. Although the survey sample size was small ($N = 29$), respondents reported on relatively large, in some cases statewide, efforts to increase CRC screening. For the qualitative study, only a subset of 29 ($n = 14$) grantees was interviewed; therefore, the range of reported navigation activities and descriptions is limited to this purposive sample. Finally, separation of grantees using colonoscopy versus FOBT for screening promotion was not possible and affected promotion-related analyses. Strengths of this study include the focus on a national program, high participation rate in the grantee survey and CDC reports, and the use of multiple methods and data sources to characterize PN in the CRCCP.

In summary, patient navigators play a critical role in the CRCCP assisting medically underserved men and women overcome substantive barriers to access clinical services and complete CRC screening. Data collected in future years of the CRCCP will allow us to examine how the implementation of PN changes over time, especially with the advent of the ACA.

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TABLE 1

Information on CRCCP Patient Navigators for Screening Provision and Screening Promotion^a

Background and Education of Navigators	Screening Provision (n = 24), n (%)	Screening Promotion (n = 18), n (%)
Experience working with the priority population/community	18 (75)	12 (67)
Background of navigators ^b		
Nursing	12 (50)	8 (44)
Social work	2 (8)	3 (17)
Health care	11 (46)	...
Public health	13 (54)	10 (56)
Cancer survivor	0 (0)	0 (0)
Community lay health/natural helper	7 (29)	9 (50)
Other	3 (13)	5 (28)
Don't know	1 (4)	...
Education level		
Less than high school	2 (8)	...
High school/GED	...	1 (6)
Associate	1 (4)	2 (11)
Nursing	9 (38)	7 (39)
College or higher	7 (30)	5 (28)
Other	5 (21)	3 (17)
Number and funding support of navigators per grantee		
Number of patient navigators/case managers per grantee, <i>M</i> (SD)	4.63 (2.7) n = 16	5.69 (2.8) n = 13
Number of FTE patient navigators/case managers per grantee, <i>M</i> (SD)	3.94 (3.0) n = 16	4.23 (3.1) n = 13
Number of screening provider sites with program-funded patient navigators/case managers, <i>M</i> (SD)	4.79 (3.4) n = 19	5.07 (3.3) n = 14
Reimbursement methods for patient navigators		
FTE funding support to provider(s)	7 (29)	7 (39)
Per patient navigation reimbursement based on patients screened	7 (29)	4 (22)
Grantee staff serve as navigators/case managers	8 (33)	4 (22)
In-kind	5 (21)	3 (17)
Other	5 (21)	4 (22)

Abbreviations: CRCCP, Colorectal Cancer Control Program; FTE, full-time equivalent.

^aScreening provision refers to patients screened with Centers for Disease Control and Prevention's CRCCP funds. Screening promotion refers to patients whose screening is paid by other sources.^bRespondents could check more than 1 category.

TABLE 2

Patient Navigation Activities Conducted by CRCCP-Supported Navigators for Screening Provision and Promotion

PN Activity	Screening Provision Grantees (n = 24), n (%)	Screening Promotion Grantees (n = 18), n (%)
Patient recruitment	17 (71)	16 (89)
Assessment of patient barriers to screening	23 (96)	17 (94)
Patient education about CRC screening modalities	24 (100)	17 (94)
Scheduling screening appointments	20 (83)	15 (83)
Arranging transportation to/from screening appointments	18 (75)	13 (72)
Peer support for cultural or emotional concerns about screening	13 (54)	9 (50)
Arranging dependent care so patients can go to screening appointments	9 (38)	5 (28)
Arranging or providing translation services	16 (67)	13 (72)
Assisting patients with cancer to get treatment	22 (92)	13 (72)
Other PN activities	5 (21)	3 (17)
Program provides other screening provision services that do not involve patient navigators	6 (21)	...
Colonoscopy (main test)	n = 12 ^a	n = 18 ^b
Making reminder calls for colonoscopy appointments	11 (92)	15 (83)
Making reminder calls for bowel preparation	11 (92)	11 (61)
Assisting patients to access bowel preparation materials	10 (83)	15 (83)
Meeting patients at endoscopic appointment	7 (58)	5 (28)
Tracking patients to be sure they complete colonoscopy	11 (92)	13 (72)
Making follow-up calls after colonoscopy	10 (83)	12 (67)
FOBT (main test)	n = 11 ^a	
Making reminder calls to return FOBT/FIT kits	11 (100)	10 (56)
Tracking patients to ensure they return FOBT/FIT kits	11 (100)	9 (50)

Abbreviations: CRC, colorectal cancer; CRCCP, Colorectal Cancer Control Program; FIT, fecal immunochemical test; FOBT, fecal occult blood testing; PN, patient navigation.

^aThis is limited to grantees that use this test as the primary test for screening provision.

^bFor screening promotion, we are unable to determine the number of grantees using colonoscopy as the main test versus FOBT as the main test; therefore, the total number of grantees using PN (n = 18) for screening promotion is used as the denominator.

TABLE 3

Characteristics of CRCCP PN for Screening Promotion

	n (%)
Total number of patients navigated in the past year	
1–100	0 (0)
101–500	8 (44)
501–1000	6 (33)
1001–5000	2 (11)
>5000	0 (0)
Don't know	2 (11)
Number of partner organizations engaged in PN efforts	
None	1 (6)
1	3 (17)
2–5	8 (44)
6–10	4 (22)
10	2 (11)
Primary partner organization role (n = 17)	
Partner organization leads PN	6 (35)
CRCCP organization leads PN	7 (41)
CRCCP and partner colead PN	4 (24)
Primary partner organization type (n = 17)	
Federally qualified health center	4 (14)
Local health department	4 (14)
Comprehensive Cancer Coalition	2 (7)
Private and/or nonprofit health care system	2 (7)
Academic institution	1 (4)

Abbreviations: CRCCP, Colorectal Cancer Control Program; PN, patient navigation.