

# Colorectal cancer education and screening program for the un- or under-insured in a primarily rural setting in Northeast Texas: Design and methods

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## ABSTRACT

Although early detection and screening for colorectal cancer (CRC) saves lives, screening rates remain suboptimal, especially for minorities, underserved populations, older adults (>60), men, un/under insured, and those living in rural settings. The goal of the colorectal cancer education and screening program is to target the un- or under- insured in a 19-county primarily rural target area to provide: 1) education concerning CRC and CRC screening to 12,000 individuals, and 2) CRC screenings (colonoscopy and/or fecal immunochemical test [FIT]) to 5,1613 un- or under- insured individuals. The education outreach team targets local health fairs, clinics, churches, etc. to educate individuals on CRC and the importance of screening. The program aims to then have those individuals electively undergo a colonoscopy and/or a FIT test. The number of those educated and screened is recorded. The results related to colonoscopy, FIT, and follow-up are collected. Primary outcomes include number of individuals educated, number of FIT test/colonoscopies performed and results of screening procedures. This education and screening outreach program is designed to reach primarily rural and underserved populations eligible for colorectal screening. Results of efficacy of program will advance knowledge on how to conduct colorectal cancer outreach programs in rural settings.

**KEYWORDS:** colorectal cancer; rural colorectal cancer outreach program; colonoscopy; FIT testing; uninsured; underinsured

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## 1. INTRODUCTION AND RATIONALE

### 1.1 Burden of colorectal cancer and the importance of early screenings

Colorectal cancer (CRC) prevention is an important public health issue. CRC is the fourth most common cancer and the fourth most common cause of malignancy-related death in the United States (U.S. Cancer Statistic Working Group, 2018). Mortality can be significantly reduced through regular CRC screenings (Friedrich et al., 2015). CRC lends itself well to public health initiatives as it is a slowly progressive disease that can be cured if treated early. Specifically, the detection and removal of precancerous polyps can prevent colorectal cancer with recent reports reporting subsequent reduced mortality by 67% (Doubeni et al., 2018; Lieberman et al., 2012). CRC survival is dependent upon early detection, thus, highlighting the importance of early screenings (Levin et al., 2008). Although screenings save lives, screening rates remain suboptimal, especially for minorities, underserved populations, older adults (>60), men, un/under insured, and those living in rural settings (Alteri et al., 2014; Salas et al., 2014).

### 1.2 CRC screening methods

Two common methods for CRC screening are colonoscopy and the fecal immunochemical test (FIT). Colonoscopy is considered the gold standard for CRC screening due to its ability to screen and consequently remove precancerous polyps (Friedrich et al., 2015). However, there are significant barriers to patients undergoing a colonoscopy such as education, a significant financial and temporal commitment, as well as fear or avoidance of the invasive procedure. For example, patients often are not aware they need the procedure, need to take time off work, prep in advance, arrange transportation (it is not recommended to drive afterward), and personally finance the procedure.

Finally, there is an additional burden of the fear or avoidance of the procedure. While colonoscopy is considered the gold standard in the medical profession, FIT seems to be better accepted (Segnan et al., 2007).

FIT offers an alternative to the financial, temporal, and personal barriers of a colonoscopy. FIT is an inexpensive CRC screening option that allows patients to send in a stool sample to a laboratory, collected at their own convenience. This eliminates the need for prep, transportation, fear and avoidance of an invasive procedure, time off work, and financial burden for many patients with a normal result. While this can be especially advantageous to the un- or under-insured, it is not a complete CRC screening method on its own (Quintero et al., 2012). FIT test results yield either a normal or abnormal result. After an abnormal test result, patients are urged to undergo a colonoscopy.

### 1.3 CRC in Northeast Texas

Northeast Texas is a 35-county area that is home to over 1.5 million individuals (Nehme et al., 2016). It consists of primarily rural communities, with few small metropolitan statistical areas. CRC incidence and mortality is higher in this rural setting (Cancer Prevention & Research Institute of Texas, 2010). Specifically, the age-adjusted incidence (43.3-43.6 in Northeast Texas vs. 38.1 in Texas and 38.27 in the United States) and CRC mortality (15.8-16.9 in Northeast Texas vs. 14.4 in Texas and 14.1 in the United States) far exceed state and national levels (National Cancer Institute, 2017; Texas Cancer Registry, 2018a, b).

### 1.4 Rationale for targeting improving CRC screening rates in Northeast Texas

The U.S. Department of Health and Human Services' current goal is to achieve a 70.5% CRC screening rate (U.S. Department of Health and Human Services,

2018). However, even with the availability of both screening methods, CRC screening rates remain suboptimal in the general public (62.4%; (U.S. Department of Health and Human Services, 2018) and in rural communities (58.2% (U.S. Department of Health and Human Services), with rates being increasingly suboptimal in Northeast Texas (44.63% (Hall, 2018)). They are even lower among the uninsured (25.1%). The high CRC prevalence and lower screening rates in the Northeast Texas region represent a growing concern. The high incidence and mortality rates of CRC may be due to factors such as non-adherence to cancer screening recommendations, diagnosis of cancer at a later stage, and higher cancer mortality, which are more likely among rural residents (Cole et al., 2012; Fan et al., 2012; Hines et al., 2014). With evidence demonstrating the slow progression of the disease and proven efficacy of CRC screening to reduce cancer mortality (Doubeni et al., 2018; Friedrich et al., 2015), it is imperative that public health programs develop programs that target populations with historically low rates of screening, such as the un/under insured, older populations, minorities, underserved populations, and those living in rural settings. The current program aims to target these individuals.

### **1.5 Challenges of a colorectal cancer education and screening program in a primarily rural setting for the un- or under-insured**

Living in a rural or mostly rural community offers unique challenges to implementing a colorectal education and screening program targeting the un- or under- insured. Challenges to screening such as a lack of education concerning the importance of screening and the different screening options are common. Dissemination of educational information is also onerous as residents are widespread and various events (e.g. health fairs) do not attract the

same number of participants as in urban settings. Transportation problems often prove burdensome in the region. Specifically, residents often must travel long distances to seek care and the number of specialists in the area is often limited. This problem intensifies for older adults or for those who are un- or under- insured. Public transportation is mostly lacking in the area, limiting ones' ability to return home following the procedure, as driving is restricted for safety reasons. Therefore, seeking preventive services such as colonoscopies and/or FIT may not be a priority for individuals in these communities.

### **1.6 The University of Texas Health Science Center at Tyler (UTHSCT) CRC education and screening program for the un- or under-insured**

The goal of the UTHSCT CRC education and screening program is to target the un- or under-insured in a 19-county primarily rural target area concerning CRC education and screening over a 5-year period (Years 1 and 2 targeted 7 counties with expansion into 19 counties for Years 3-5). Specifically, the program aims to provide: 1) education concerning CRC and CRC screening to 12,000 individuals, and 2) CRC screenings (colonoscopy and/or FIT) to 5,161 un- or under- insured individuals.

## **2. METHODS**

### **2.1 Overview**

Process flow of the program is detailed in Figures 1-3. Figure 1 details the initial participant process. Figure 2 details participant process when electing FIT testing, while Figure 3 details participant process when undergoing colonoscopy. This is an education and screening program targeting the un- or under-insured. The education outreach team targets local health fairs, clinics, churches, etc. to educate individuals on CRC and the importance of screening. The program aims to then have those individuals

electively undergo a colonoscopy and/or a FIT test. The number of those educated and screened is

recorded. The results related to colonoscopy, FIT, and follow-up are collected.

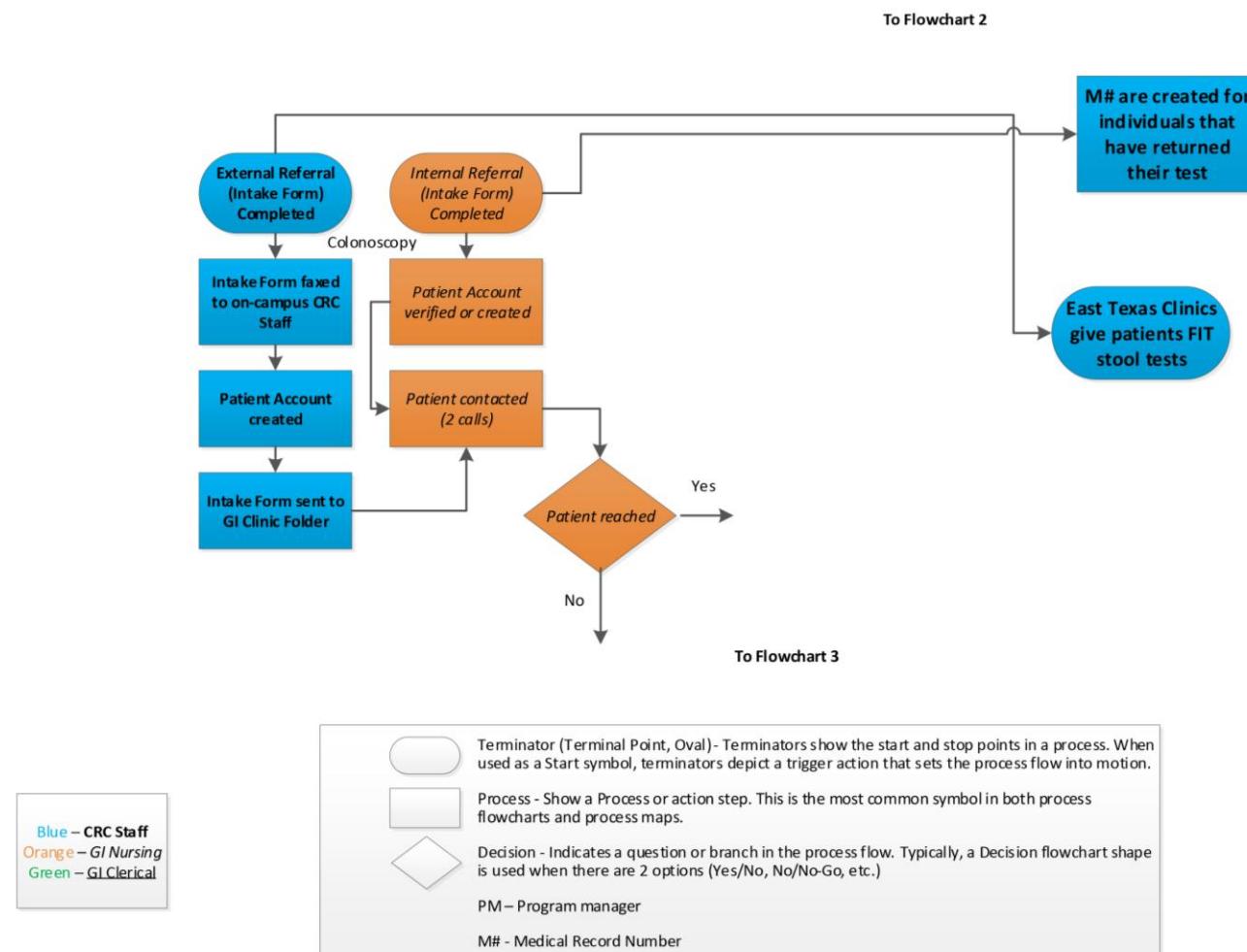


Figure 1. Initial Participant Process

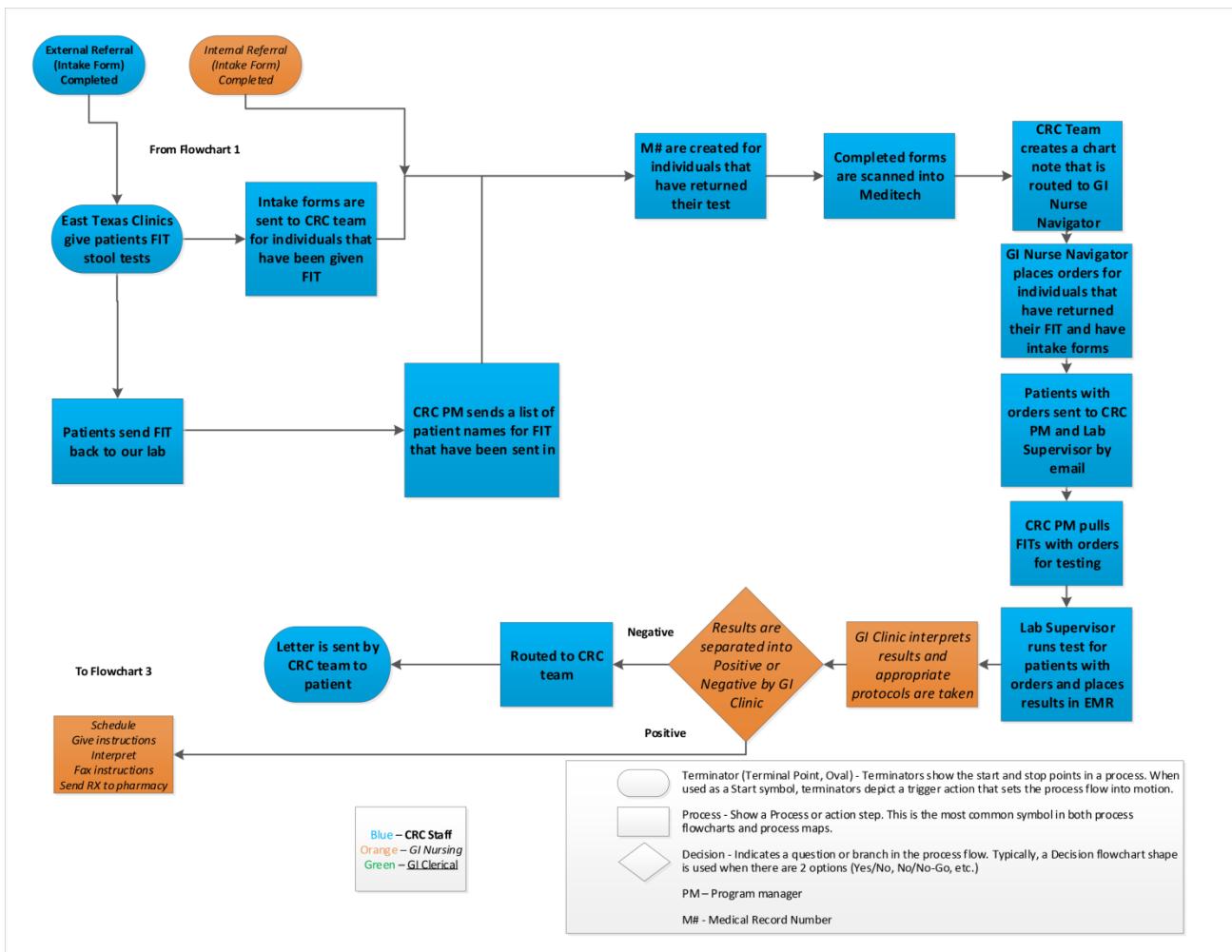


Figure 2. Participant FIT Process

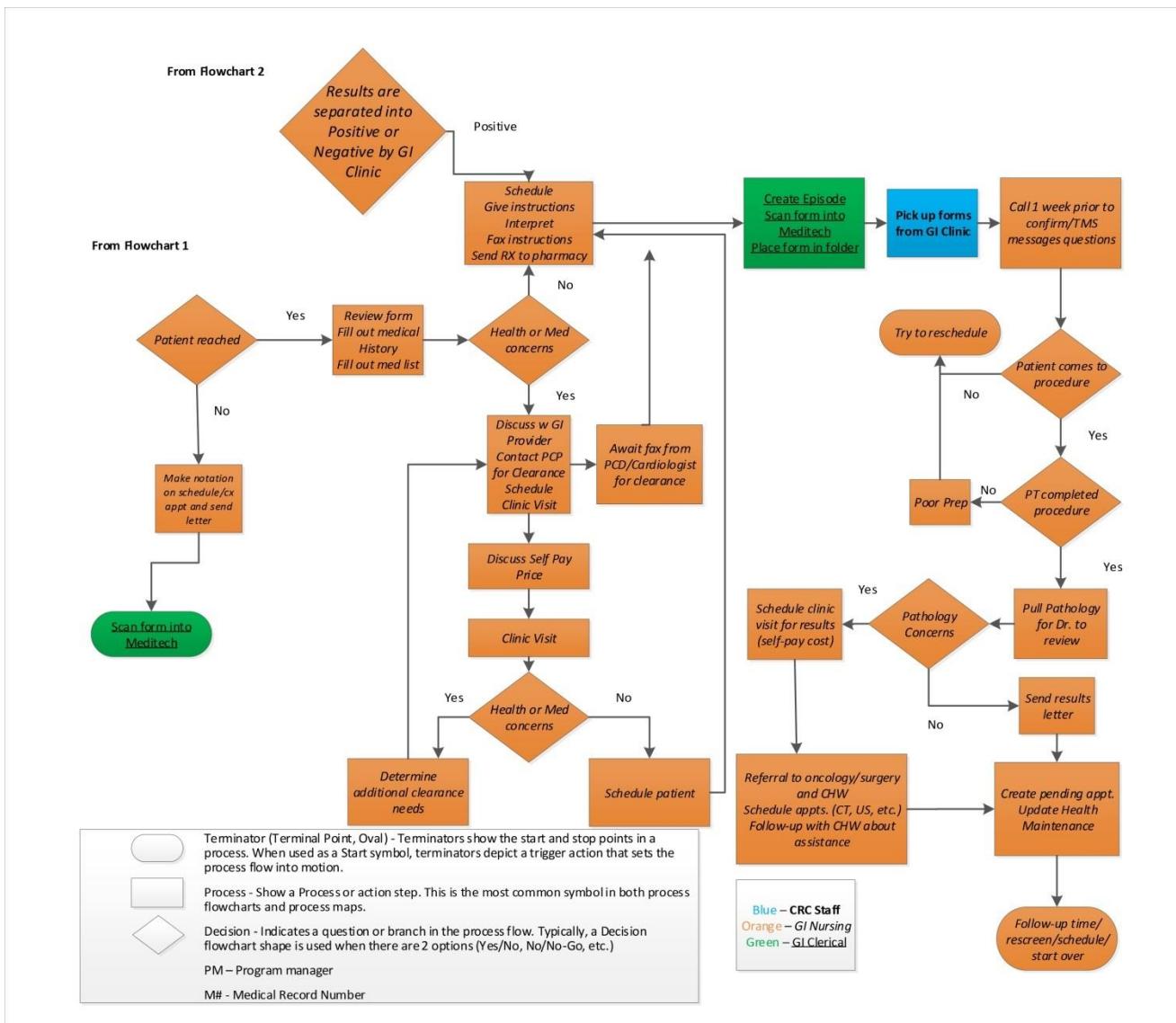


Figure 3. Participant Colonoscopy Process

## 2.2 The program team

The members of the team consist of a Program Director, Co-Program Director, Program Manager, an Outreach Education Coordinator, Program Specialist, Nurse Navigator, and 3 Health Education Coordinators. The Program Manager, Outreach Education Coordinator, Program Specialist, Nurse Navigator, and Health Education Coordinators have gone through the Texas CHW certification training. They maintain their certification by completing CHW continuing education requirements. In addition, they are trained in Motivational Interviewing.

## 2.3 Recruitment setting, eligibility, and enrollment

Recruitment had both a community based and a clinical focus. Our strategy involved reaching out to individuals to make them aware of the need to undergo CRC screening, educating them about their screening options, performing the screening methodology of choice (FIT or colonoscopy), providing access to treatment for CRC, and providing follow-up. Individuals are recruited from clinics at UTHSCT, health fairs, charity clinics, local health departments and districts, and federally qualified health centers (FQHCs). The primarily rural

19-county region, known as Northeast Texas, has an area of about 14,762 (National Association of Counties, 2017) square miles with a total population of 2,167,769 (United States Census Bureau, 2017) in 2017. Eligibility for colonoscopy/FIT are determined after education outreach and/or physician recommendation.

To determine eligibility, US Preventive Services Task Force (USPSTF) guidelines, which recommend screening all races/ethnicities between the ages of 50 and 75, were followed. Individuals are eligible to participate if they are between 50 and 75 years of age, speak English or Spanish, are un- or under-insured, do not have a medical reason for not undergoing the procedure(s) (e.g. taking blood thinners), and have not been previously diagnosed with CRC. Individuals also couldn't have had a colonoscopy in the last ten years, a sigmoidoscopy in the last five years, or a stool test in the last year before becoming eligible for the Cancer Prevention and Research Institute of Texas (CPRIT) screening program.

#### **2.4 CRC education**

Our community-based approach reaches out through social media and community events. Social media is used through Facebook, Twitter and YouTube. Educational sessions at various community venues and health fairs throughout East Texas stressed the need for routine screenings and recruited individuals from these events. Community health workers (CHWs), in conjunction with the program manager and other support staff, coordinated these community educational activities, with the support of many church and minority business groups to spread awareness of the screening program and provided venues for community education. An educational tool that was used in the community outreach program was a

giant inflatable colon. This colon model includes various stages of CRC progression (from normal through polyps to invasive cancer). This among other tools served as an educational and interactive exhibit during outreach activities by CHW's to educate communities.

Promotion is also being accomplished through partnerships and outreach with various community organizations including churches, workplaces, and barber/beauty shops. Individuals attending these meetings are asked to listen to a brief presentation about CRC screening, review a tailored decision-aid, complete a short intake form to determine eligibility, and sign a commitment specifying which screening option they plan to choose if eligible. The intake form includes demographics, screening status, health insurance, screening method preference, reminder preferences, barriers to participation, and intention to undergo screening. The intake form responses are entered and maintained in an electronic community outreach registry.

Our clinical based approach involved us enlisted the help of multiple clinical partners to optimize recruitment. Our partners include an academic medical center, a charity clinics, local health departments and districts, and FQHCs. We work with providers in primary care at UTHSCT and at other healthcare facilities to refer their patients for CRC screening. The focus of our recruitment is on the un- and under-insured.

We worked with the American Cancer Society (ACS) to align cancer control opportunities and solutions with the needs and challenges of our health center, emphasizing sustained capacity building to result in improved public health outcomes. Specifically, the ACS assisted us by providing strategic planning guidance, provider and CHW education to optimize client and provider interventions. The ACS has

trained CPRIT and clinical staff. The partnership with ACS has increased our ability to educate providers and staff to optimize participant education and CRC screening. The ACS also provided linkages to community resources and other health systems to support sustained continuity of care.

## 2.5 CRC screening

Once all inclusion/exclusion criteria have been met, participants are offered colonoscopy and/or FIT test based on their preference and/or provider recommendation. Our nurse navigator will identify eligible individuals from a weekly report. The navigator will facilitate the coordination of the participant through the system for colonoscopy. Once it was determined that participants who were deemed un- or under- insured were unable to pay for services, screenings were provided free-of-charge. In addition, participants undergoing a colonoscopy received a \$20 gift card for transportation upon completion of a colonoscopy. If a participant did not undergo proper bowel prep and the colonoscopy is unsuccessful, an alternative date is scheduled. Participants who elected to have a FIT were scheduled for a colonoscopy if they had an abnormal FIT result (and subsequently received the same \$20 gift card upon completion of services). The team works diligently to contact participants in regard to mailing FIT to the appropriate addresses, recontact individuals with their results and to schedule colonoscopy appointments with those who elect colonoscopy or receive an abnormal FIT test.

If no additional procedures are immediately warranted, after the procedure, the patient is sent a letter detailing their results and when they should follow-up. They are also spoken to about attaining a primary care physician, if they do not already have one. If something additional is required, the patient is called and asked to return to the clinic. During that

visit, the Nurse Navigator is present for support and clarification of treatment plan and decision making when diagnosis is given. For participants that require surgery first, the navigator will assist, if necessary, in treatment plan decisions (post-op radiation, post-op radiation and chemotherapy, or post-op chemotherapy). The navigator will continue to follow the participant through the continuum of care.

If individuals who were educated at local events are found to have adequate insurance, they are referred to colonoscopy/FIT services, but are not financially compensated for their procedures. For individuals who were uninsured and required cancer treatment, CHWs and a Nurse Navigator assisted in finding alternative methods of funding for future procedures if needed. These alternative methods, included but were not limited to, the Affordable Care Act/Marketplace insurance, Medicaid, the County Indigent Health Care Program, or hospital insurance. For surveillance, the navigator will hand-off patients to the oncology team but will ensure follow-up of CRC screening is scheduled. For alternative pathways, Nurse Navigator will hand-off participant to medical/radiation oncology nurse and receive updates periodically. The Nurse Navigator will still ensure follow-up of CRC screening is scheduled. Due to the difficulty of tracking those individuals, data is only available for the un- or under- insured.

## 2.6 Challenges concerning no-show rates.

Noncompliance to completion of a CRC procedure is very common, especially with colonoscopy. Our program isn't unique to the many barriers faced by individuals including coordinating transportation, fear the test is painful, embarrassment, and/or fear of abnormal findings (Chen et al., 2008). Our program uses CHWs to call individuals using motivational interviewing for participants that cancelled or no-showed to their appointments. Our GI clinic also

attempts to reach out to individuals via phone calls as well. If unable to reach via phone, a letter is sent to their listed address inviting them to call to reschedule their appointment. We also work with community partners and update the clinics on the status of individuals that were referred to us by them. This was done so if an individual were to return to their primary care clinic before contacting us, the clinic would be able to get in contacts with the individual again.

## 2.7 Data collection

Data collection is conducted at UTHSCT and outreach events. Data is comprised of self-reported questionnaire items and medical records. Reports are collected on a quarterly basis.

### 2.7.1 Education outreach data

The data collected at outreach events includes: Name, phone number, address, date of birth, race, ethnicity, gender, insurance status, if individuals are a health professional, if they have had a colorectal screening in the past, and if they would like to receive more information. This data was collected at outreach events by project staff. Sign-in sheets were then scanned into password-protected folders and the data was transferred into an excel sheet.

### 2.7.2 Demographic data

Demographic data is collected from medical chart data and through survey questionnaires. Data collected include, age, race, ethnicity, zip code, family history of CRC, previous CRC screenings, and insurance status.

### 2.7.3 Colonoscopy data

Data concerning colonoscopy procedures is collected from medical chart data. The data includes the date of colonoscopy, bowel prep (adequate/insufficient), result of colonoscopy,

whether additional colonoscopies were warranted by the treating physicians.

### 2.7.4 FIT data

Data concerning FIT is collected from medical chart data. The data includes the date of FIT test, test result, duration of time to colonoscopy following abnormal FIT result.

## 3.1 DISCUSSION

### 3.1 Need for intervention to increase CRC education and screening rates

CRC screening to prevent cancer is only effective if individuals elect to undergo screening services (Friedrich et al., 2015). Despite the efficacy of screening services such as colonoscopy and FIT, screening rates remain suboptimal (Alteri et al., 2014; Levin et al., 2008; Salas et al., 2014). Therefore, interventions targeting improvement in education and screening regarding CRC are crucial. Public health programs can initiate such programs and target populations with low screening rates. This will help to reduce the incidence of CRC and CRC mortality. The un/underinsured can particularly benefit from such programs, as they would not regularly undergo this preventive screening, as it would be an added medical cost. In addition, the un/under insured are particularly vulnerable as they would most likely not be able to afford treatment if CRC would develop, highlighting the importance of public health programs adopting similar initiatives to increase education and subsequent CRC screening in populations with low screening rates. An additional barrier to many potential programs may include the rurality of the proposed region for intervention. Whereas, the education and screening of thousands of adults may be achieved with more ease in urban areas, teams working in rural settings face unique challenges to motivate individuals to undergo

screening. The primary barrier to care that is unique to rural areas is distance. Interventions programs must persuade individuals about the importance of CRC screening and follow-up despite the additional burden of transportation and distance.

### 3.2 Potential limitations and methodological considerations

The current program has several limitations. First, while some individuals will elect to undergo colonoscopy first, others will undergo colonoscopy after a positive FIT test. However, both groups will have many individuals who fail to arrive for their scheduled colonoscopy due to transportation issues and despite receiving a \$20 gift card for travel. Unfortunately, to the current program does not provide transportation services to individuals. Second, as mentioned earlier, many individuals choosing to undergo FIT testing will not follow-up with colonoscopy after an abnormal FIT test result. This will hinder assessing the efficacy of FIT test in detecting polyps. Similarly, those with a negative FIT will not undergo a colonoscopy. Third, the degree of education retained by individuals will not be able to be assessed due to the lack of time provided in health fairs. Only the number educated can be assessed.

### 3.3 Conclusion and implications

In conclusion, the CRC education and screening program aims to increase education and CRC screenings in a primarily rural population in Northeast Texas with low CRC screening rates and high CRC incidence and mortality. Results from this program have the potential to advance knowledge on effective ways to increase CRC screenings among underserved populations. Due to the nascentcy of FIT testing, evaluation of programs utilizing both FIT and colonoscopy are limited. The current program will provide insight into the advantages and

disadvantages to each method in a primarily rural setting. Finally, it may also provide a method to those who were educated but did not undergo screening at the time, to undergo screening in the future, or for those who underwent screening to continue with screening methods outside of the program.

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### Conflict of interest

The authors declare that no competing or conflict of interests exist. The funders had no role in study design, writing of the manuscript, or decision to publish.

### Authors' contributions

Carlton Allen and Paul McGaha contributed to the acquisition of data and the conduct of the project. Gabriela Orsak, Anastasia Miller and Karan Singh contributed to the statistical analysis of the project and generated the initial draft of the article.

### REFERENCES

- Alteri, R., Kramer, J., and Simpson, S. (2014). Colorectal Cancer Facts and Figures 2014-2016. Atlanta: American Cancer Society, 1-30.
- Cancer Prevention & Research Institute of Texas (2010). Colorectal cancer in Texas: A closer look.
- Chen, L.A., Santos, S., Jandorf, L., Christie, J., Castillo, A., Winkel, G., and Itzkowitz, S. (2008). A program to enhance completion of screening colonoscopy among urban minorities. *Clinical Gastroenterology and Hepatology* 6, 443-450.
- Cole, A.M., Jackson, J.E., and Doescher, M. (2012). Urban-rural disparities in colorectal cancer screening: cross-sectional analysis of 1998–2005 data from the Centers for Disease Control's Behavioral Risk Factor Surveillance Study. *Cancer medicine* 1, 350–356.
- Doubeni, C.A., Corley, D.A., Quinn, V.P., Jensen, C.D., Zauber, A.G., Goodman, M., Johnson, J.R., Mehta, S.J., Becerra, T.A., Zhao, W.K., et al. (2018). Effectiveness of screening colonoscopy in reducing the risk of death from right and

- left colon cancer: a large community-based study. *Gut* 67, 291-298.
- Fan, L., Mohile, S., Zhang, N., Fiscella, K., and Noyes, K. (2012). Self-Reported Cancer Screening Among Elderly Medicare Beneficiaries: A Rural-Urban Comparison. *The Journal of Rural Health* 28, 312-319.
- Friedrich, K., Grüter, L., Gotthardt, D., Eisenbach, C., Stremmel, W., Scholl, S., Rex, D.K., and Sieg, A. (2015). Reduced mortality in colorectal cancer patients diagnosed by screening colonoscopy. *GI Endoscopy* 2015, 133-137.
- Hall, J. (2018). Colorectal cancer screening data, G. Orsak, ed.
- Hines, R., Markossian, T., Johnson, A., Dong, F., and Bayakly, R. (2014). Geographic residency status and census tract socioeconomic status as determinants of colorectal cancer outcomes. *American journal of public health* 104, e63-e71.
- Levin, B., Lieberman, D.A., McFarland, B., Smith, R.A., Brooks, D., Andrews, K.S., Dash, C., Giardiello, F.M., Glick, S., Levin, T.R., et al. (2008). Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps, 2008: a joint guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology. *CA Cancer J Clin* 58, 130-160.
- Lieberman, D.A., Rex, D.K., Winawer, S.J., Giardiello, F.M., Johnson, D.A., and Levin, T.R. (2012). Guidelines for colonoscopy surveillance after screening and polypectomy: a consensus update by the US Multi-Society Task Force on Colorectal Cancer. *Gastroenterology* 143, 844-857.
- National Association of Counties (2017). Texas.
- National Cancer Institute (2017). SEER cancer statistic review (CSR) 1974-2014.
- Nehme, E., Elerian, N., Morrow, J., Mandell, D., Puga, E., Patel, D., and Lakey, D. (2016). The Health Status of Northeast Texas 2016 (Austin, TX: UT Health Northeast/University of Texas System Office of Population Health).
- Quintero, E., Castells, A., Bujanda, L., Cubiella, J., Salas, D., Lanas, Á., Andreu, M., Carballo, F., Morillas, J.D., and Hernández, C. (2012). Colonoscopy versus fecal immunochemical testing in colorectal-cancer screening. *New England Journal of Medicine* 366, 697-706.
- Salas, D., Vanaclocha, M., Ibáñez, J., Molina-Barceló, A., Hernández, V., Cubiella, J., Zubizarreta, R., Andreu, M., Hernández, C., and Pérez-Riquelme, F. (2014). Participation and detection rates by age and sex for colonoscopy versus fecal immunochemical testing in colorectal cancer screening. *Cancer Causes & Control* 25, 985-997.
- Segnan, N., Senore, C., Andreoni, B., Azzoni, A., Bisanti, L., Cardelli, A., Castiglione, G., Crosta, C., Ederle, A., and Fantin, A. (2007). Comparing attendance and detection rate of colonoscopy with sigmoidoscopy and FIT for colorectal cancer screening. *Gastroenterology* 132, 2304-2312.
- Texas Cancer Registry (2018a). Age-adjusted cancer mortality rates in Texas Colon & Rectum, 2011-2015 by public health region.
- Texas Cancer Registry (2018b). Age-adjusted invasive cancer incidence rates in Texas colon & Rectum, 2011-2015 by public health region.
- U.S. Cancer Statistic Working Group (2018). U.S. Cancer Statistics Data Visualizations Tool, based on November 2017 submission data (1999-2015) (U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute,).
- U.S. Department of Health and Human Services. Healthy People 2020 (Washington DC: U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion).
- U.S. Department of Health and Human Services (2018). C-16 Increase the proportion of adults who receive a colorectal cancer screening based on the most recent guidelines.
- United States Census Bureau (2017). American Fact Finder.