Mining the Colorectal Cancer Screening Network to explore, practices, policies, and challenges in colorectal cancer screening

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Executive Summary

Achieving higher rates of colorectal cancer screening is imperative to preventing and detecting cancer; however, there are several factors that contribute to a state or program’s ability to achieve a higher rate of screening. The National Colorectal Cancer Screening Network is an informal volunteer group of individuals representing organizations involved in colorectal cancer prevention programming and activities in states, tribes, and territories from across the US. Mining the resources of the National Colorectal Cancer Screening Network is one strategy to further explore such factors using a responsive convenience sample, as network members represent a diverse geographic region, while also having a unique view of the impact that practice and policy have on colorectal cancer screening delivery in the field. A literature review, preliminary survey, key informant interviews, and a detailed survey were used to assess the landscape of colorectal cancer screening on local, state, and national levels. Themes that emerged from this analysis were related to colorectal cancer screening policy, access, and capacity.

The majority of participants in the preliminary survey (N=85) indicated that their main source of funding for their program was through the Centers for Disease Control’s Colorectal Cancer Control Program (CRCCP) (58%). However, there were discrepancies in answers, such as if Medicaid covers CRC screening in particular states, which pointed to the need for a more detailed survey. Participants in the detailed survey (N=41) represented 22 states and the District of Columbia. Similar to the first survey, 56% of participants reported that they receive CDC CRCCP funding. Overall, participants demonstrated strong overall awareness of key issues, such as a screening colonoscopy being classified as a diagnostic when a polyp is found and the resulting change in patient copays. Participants also reported they had heard of providers limiting the number of Medicare and Medicaid patients they will accept, largely due to reimbursement issues. Looking forward to when the Affordable Care Act expands Medicaid eligibility, 53% of respondents said that insufficient provider capacity will be problematic to delivery of colorectal cancer screening to the increased population.

Although health care reform strives to expand coverage to a larger number of individuals, several issues will remain and will likely be exacerbated.

- For instance, unexpected patient costs for screening colonoscopies that become diagnostic is a current problem. A recommendation to address this problem among
private payers is to work with insurers to reform billing code policies and work to ensure such policies are being implemented in practice. Within the Medicare program, it is likely that federal legislators will need to address this problem. A multifaceted approach will be needed to assure all the necessary steps in the process are changed. Although the results demonstrated that detailed survey participants acknowledge this as a problem, the majority of respondents indicated that their state has not proposed a policy to ensure that a screen remains preventive rather than diagnostic (54%) among private insurers, or they did not know if a policy had been proposed (41%). A few states, such as South Carolina, report success working with private insurers. In addition, this concern was further extended to using FOBT/FIT tests for screening. For instance, one survey respondent stated, “We are anxious to work with others to get the Medicare policies and provider billing reformed so that patients who have colonoscopies that were intended to be screening colonoscopies remain screening, even if something is found on colonoscopy. Also that colonoscopy as follow up to positive FOBT/FIT would be covered completely.”

- A second recommendation is to continue to focus on working with employers to implement worksite wellness policies. Even if there is more widespread access to coverage due to health care reform measures, people will still need to get time off work to attend appointments. This is particularly true for those undergoing colonoscopy screening. Respondents to the detailed survey listed several ongoing efforts in various states. In Mississippi, for example, work is being done to offer paid time off for screening, removing one barrier to screening.

- A third recommendation is to provide more policy training for the public health workforce. The majority of the survey participants were aware of current barriers to screening. However, in regards to the diagnostic billing coding, only one respondent was aware of a policy that had been proposed to address this problem. Training on how to act on such issues could provide public health professionals with the tools necessary to move such initiatives forward.

- Finally, a final recommendation is to implement a survey with other groups whose perspective and experiences are important, such as medical providers and a revised survey to the tribal nations. Providers could offer insight on reimbursement issues, how frequently primary care or endoscopic providers limit Medicaid or Medicare patients, and the corresponding impact on CRC screening. Their foresight on whether provider capacity will be sufficient once health care reform is implemented would be helpful in addressing related issues. The system and policy challenges to increase screening in tribal communities are very different, as reflected by one participant in the survey, and warrants further explanation.
Introduction

Describing the challenges being encountered by those trying to promote and increase CRC screening at the ground level, such as the public health workforce, can be very useful in identifying actions at the national or local level that may have substantial effects on increasing CRC screening rates. The aim of this project, sponsored by the National Colorectal Cancer Roundtable Policy Action Task Group with funding from CDC Cooperative Agreement Number U50/DP001863, was to gather information from members of the National Colorectal Cancer Screening Network and their contacts about practices and policies and challenges associated with colorectal cancer screening. The network originated in 2007, when New York and CDC convened an informal meeting among states involved in colorectal cancer screening. With leadership provided by the states, the Network has grown to about 300 members, representing national, regional, state, local, and tribal organizations from 42 states (See appendix A). The purpose of the National Colorectal Cancer Screening Network is to promote collaboration to increase colorectal cancer screening through information-sharing among its members of nationally-distributed public health and health care professionals. The Network generally meets bi-annually at National Colorectal Cancer Roundtable conference in fall and the Prevent Cancer Foundation’s Dialogue for Action meeting in the spring. This Network was chosen to serve as the survey population due to the geographic distribution of its members and its composition of public health professionals working within the field. However, it is important to note that the Network is a convenience sample, and is not exhaustive in its representation of all colorectal cancer screening programs.

The two components of the project are:

- Exploring issues around medical providers and access to medical care; and
- Exploring issues around state and local practices and policies related to insurance and colorectal screening.

With health care reform occurring at a national level by 2014, these topics are important to explore as we aim to achieve higher rates of CRC screening.

Methods

A literature review, including CRC screening guidelines, existing coverage for CRC screening, as well as overviews of proposed health care reform activities, was conducted to gather appropriate background information on CRC screening (See Appendix F). About 85 members participated in a preliminary survey sent out to the Colorectal Cancer Screening Network members in February 2011 prior to the Dialogue for Action Conference on Colorectal Cancer to explore potentially important policy
issues for discussion at the meeting and to guide development of a more specific survey. Some areas highlighted for exploration included inconsistency of CRC screening coverage of Medicaid, lack of knowledge about policies and practices that affect CRC screening, and a need for more understanding of the effects of health care reform on local and state level activities related to CRC screening. Please see Appendix B for details on the preliminary survey and the results of that survey.

The findings from both the literature review and preliminary survey were used to develop key informant interview questions. These key informant interviews were conducted to provide insight into key policy and practice issues surrounding colorectal cancer screening. Key informants from across the nation were identified with insight from Dr. Holly Wolf; and interviews were conducted in April and May 2011.

Key informant questions included:

1. As the (insert title/organization here), what is your role in regards to colorectal cancer screening?
2. What are two or three of the greatest barriers for individuals to receive access to CRC screening (specifically thinking about policies and practices)?
3. What kind of barriers to screening will remain even after health care reform is put into place?
4. What do you think the next steps will be in driving the consumer to be screened?
5. Is there anything else you would like to discuss/share that we haven’t that you feel is relevant?
6. Is there anyone else you think we should talk to?

A total of eight interviews were conducted. That included representatives from the following organizations: American Cancer Society Cancer Action Network, the leadership team of the Screening Network, and current and former leaderships of the National Colorectal Cancer Roundtable Policy Action Task Group. (See Key Informant Interview Guide in Appendix B for more details.) The findings from the Key Informant interviews and themes to address in the detailed survey were provided to Mary Doroshenk, Director of the National Colorectal Cancer Roundtable, for review and comment.

The results of the key informant interviews were summarized into key themes and used to develop a more detailed survey. The detailed survey was organized around the major themes of access to screening, provider capacity, and policy. The 49-question multiple choice survey was created using the online survey tool Zoomerang. Five questions provide opportunity for open ended comments. A four point Likert scale was used to answer several of the questions, in order to encourage participants to choose a non-neutral answer. In the following discussion, the Likert categories “somewhat” or “greatly” were collapsed in reporting the results. After pilot testing the questions, the 30 minute detailed survey was sent via email to a subset of the Screening Network (n = 50) who had volunteered to participate in the survey. The survey was later sent to the larger Screening Network to increase the response rate and was closed after 1 month.
Results and Discussion

Participant characteristics

Forty-one participants from 22 states and the District of Columbia completed the survey. Geographically, there were strong representation from the Southeastern, Western and Pacific Northwestern, Mid-Northern, and Northern states. There were notable gaps in participation from southwest, mid-south states, and New England in this survey. (See Figure 1.) The majority of participants (48%) were program managers, coordinators or directors. Physicians (13%), advocates/legislators (8%) and researcher/data analysts (8%) were also represented. Little participation occurred from health education professionals in the network.

Figure 1.

Distribution of Detailed Survey Participants

Fifteen states from the Center of Disease Control’s Colorectal Cancer Control Program (CRCCP) were represented. Fifty-six percent of participants reported that their state receives this funding. The CDC currently funds 25 states and 4 tribes for colorectal cancer prevention activities. Thirty-four percent of participants responded that they receive state funding, and 15% indicated that their program was not
currently funded. Other sources of funding include local funding (such as taxes and local health departments), private foundation funds and local in-kind contributions.

Figure 2 represents reported programs from both the preliminary survey and the detailed survey. Overall 90% of detailed survey participants, representing all 22 states from the survey, indicated their state had free or reduced-cost screening. Sixty-eight percent of these respondents said that programs in their state offer free or reduced-cost treatment if cancer is found. However, we are not able to determine if the programs that survey participants represent offer the treatment or if treatment is provided by another source, therefore this percentage may be an overestimate. Of those states that answered yes regarding treatment funds, 72% receive CRCCP funding. This is noteworthy, as CRCCP does not cover treatment costs. This suggests that states that have CRCCP funding may be more successful in leveraging private and state funds available to cover treatment.

Figure 2.

With respect to other payer sources for the underserved, 80% of participants responded that their state’s Medicaid coverage included CRC screening for individuals over 50, while 10% responded “no” and 10% responded “I don’t know.” This is a significant change from the earlier network survey, where 27% of participants did not know if Medicaid covered colorectal cancer screening in their state. Furthermore, preliminary survey participants who indicated that Medicaid did cover screening in their
state (66%), did not answer consistently within the same state. This suggests that respondents to the second survey were more knowledgeable about this topic or perhaps that events have transpired between the first and second survey that have increased awareness of state Medicaid coverage. Although it is reasonable to assume that there are some overlap in participants between surveys, respondents self-selected to participate, and thus it was not the exact same sample. This underscores the complexity of understanding Medicaid as a system, as coverage varies from state to state and suggests that additional training around the system at the local level will help improve utilization after health care reform.

When asked about the primary CRC screening method used in their state, 58% of respondents indicated colonoscopy, while 33% indicated FIT/FOBT. The remaining 9% indicated “other.” Reported primary screening method may differ from actual primary screening method. For example, participants in the survey reported FIT/FOBT as the primary screening method for New York; however, New York City has an extensive colonoscopy screening program. One thought is that instead of answering for the entire state, participants may have answered the question based upon their own program. See Figure 3.

Figure 3.

**Reported Primary Screening Method By State**

![Map of reported primary screening methods by state](image)

*Note. Primary screening method as reported by participants in the detailed survey. It is possible the actual primary screening method used in each state may differ.*
Policy

Cost sharing for screening tests that become diagnostic

One concern that was identified during formative research for the detailed survey was that a screening colonoscopy may be classified as a diagnostic or therapeutic procedure when a polyp is found rather than a preventive screen. This increases the individual’s out-of-pocket cost, including co-insurance, co-pays, deductibles and additional charges related to anesthesia, medications, and/or pathology fees. The survey used the broad term “out-of-pocket costs” due to the fact that the increased expenses for a diagnostic exam can take a variety of forms depending on the recipient’s insurance coverage (i.e. Medicare vs. private insurance plan). It is important to note the challenge in defining the various terms and policies related to out-of-pocket costs.

These increased out-of-pocket costs were identified as an issue with private insurance and Medicare. For example, if a Medicare beneficiary goes in for a screening colonoscopy, it will be considered a free preventive service, and they will not have any out-of-pocket costs. However, a screening colonoscopy becomes diagnostic when a physician removes a polyp or takes biopsy during the procedure. If this happens, the exam will be given a different classification and the Medicare patient will be responsible for a 20 percent co-insurance. See Appendix D for more information.

Overall, survey respondents demonstrated a high general awareness of this issue. Eighty percent responded that they had heard of the type of billing code that is used on a patient’s record affecting whether the colonoscopy is classified as a preventive screen or a diagnostic procedure in individuals with private insurance. Furthermore, when asked if they had heard about this coding issue increasing an individual’s out-of-pocket costs, 83% said yes. Seventy percent said they thought that these potentially unexpected costs would deter individuals from being screened.

Awareness was similarly high when asked about the Medicare population. Seventy-six percent of participants responded they had heard of the issue of a preventive screen becoming diagnostic in the Medicare population. Sixty percent thought that these potentially unexpected costs would deter Medicare beneficiaries from being screened.

A preventive screening becoming diagnostic when a polyp is found may also be an issue for those covered by Medicaid. However, this issue did not come up in key informant interviews and was not explored in the survey due to the program and CRC screening coverage variability state to state.

While Medicare policy can only be addressed at the federal level, states have the ability to address some private insurance policies within their state. Although detailed survey participants acknowledge this as a problem, the majority of respondents indicated that their state has not proposed a policy to ensure that a screening test remains preventive rather than diagnostic (54%) with respect to patient cost sharing, or they did not know if a policy had been proposed (41%). A few states have been successful. The one state that responded “yes” was South Carolina. According to the respondent, “BCBS
[Blue Cross Blue Shield] SC has implemented a policy that ensures that billing code used is preventive services so that no increased out of pocket is incurred. BCBS is by far the largest insurer in SC.”

Although it appears from the survey that there is not a lot of work being done currently at the state or local level to address this preventive vs. diagnostic cost sharing issue, such an effort would likely be supported by Screening Network members. The majority of participants (78%) said the most effective way to ensure lower out-of-pocket expenses for individuals with insurance would be to classify a colonoscopy as an exclusive preventive service when initiated as a screening test. In the open-ended comments section, one participant commented, “We are anxious to work with others to get the Medicare policies and provider billing reformed so that patients who have colonoscopies that were intended to be screening colonoscopies remain screening, even if something is found on colonoscopy. Also that colonoscopy as follow up to positive FOBT/FIT would be covered completely.”

Coverage for a follow-up colonoscopy after a positive FOBT/FIT screen may be of concern, which was suggested to cause a bias against using FOBT/FIT as a screening modality. Essentially, the question is whether or not a colonoscopy that is a follow up to a screening FOBT/FIT is categorized as screening or diagnostic in terms of cost sharing. One respondent noted, “I am concerned that a colonoscopy that is a follow up to a positive FOBT would not be well covered. This incentivizes people to use the more expensive screening first rather than the proven and cost effective one first.”

**Workplace wellness policies**

Workplace wellness policies were also addressed in the survey. When asked, “Are there any efforts in your state to work with employers to reform workplace policies that could increase screening?”, 51% of respondents reported that their state has efforts to work with employers, 10% replied no, and 39 percent did not know. Respondents provided details from 15 states. In Mississippi, for example, work is being done to get voluntary policies in place to offer paid time off for screening. In Kentucky, state government employees have essentially no out-of-pocket costs for preventative services through revision of their insurance plan. And in Michigan, the Michigan Cancer Consortium (MCC) is working with its 114 members to implement workplace policy change to support cancer screenings. See Workplace Wellness Activities Chart in Appendix E for more examples.

**Provider practices**

Key informant interviews indicated lack of provider recommendation for CRC screening was an important reason for patients not being screened, which is consistent with the scientific literature. The detailed survey explored whether participants felt providers not recommending CRC screening was a barrier, and if so, why. Seventy-five percent of respondents answered that this is a barrier in their state. Participants selected providers’ lack of time and lack of knowledge about screening guidelines as the most common reasons why.

States do seem to be putting policies in place to help facilitate a provider recommendation about screening. When asked about polices being implemented in their state to improve CRC screening, 93%
said they had heard about electronic record prompts or patient reminder systems; 79% said they had heard about provider education trainings; and 85% had heard about patient navigators. Record prompts, provider education and navigators can help address the concerns of lack of provider time and lack of provider knowledge. More study may be warranted to understand how widespread these tools and resources are and how successful they are in facilitating a provider recommendation about screening.

One survey participant commented that s/he felt that the most common reason physicians do not recommend screening is they think patients won’t comply with take-home testing and patients are reluctant to be screened. Citing state survey data from Alabama, “A major barrier from the physician standpoint based on our surveys is that physicians feel that patients will not be compliant with take home testing; physicians are using DRE (widely) for testing; physicians are uninformed about the FIT so don’t know whether a patient will comply with a FIT compared to a low or high sensitivity guaiac test; that patients aren't willing to undergo a colonoscopy because THEY DON'T WANT TO.”

A participant from New Hampshire commented that a lack of facility policies on recommendation and failing to track rates as the most common reasons physicians do not recommending screening. In response to the question options, they commented, “My choice would have been no office policy on how to increase screening and tracking of provider rates and giving feedback. This is the most successful strategy in NH ... If providers do not know their screening rates they believe they are always recommending screenings, which we know not to be the case.”

**Policy activities**

The survey asked questions about awareness of policy related to CRC screening. When asked if they participated in education of groups about policy related to CRC screening, 78% of respondents reported they participate in some sort of policy work. Work with community organizations or grassroots efforts was the most common type of education. See Figure 4, below:
The majority of respondents said they participated in activities varying from sometimes to often; however, only half of respondents said they had received training about policy related to CRC screening. The interest in such training was high; 77% reported they would be interested in such a training if it was offered.

**Access**

The survey addressed barriers to colorectal screening access relevant to various populations, including Medicare, Medicaid and those with private insurance.

**Medicare**

It was stated in the key informant interviews that primary care providers sometimes limit Medicare patients, which theoretically could result in a loss of access that could be a barrier to screening. When asked about primary care providers limiting Medicare patients, 56% of detailed survey participants said they had heard of or had experience with the issue. Of those who had heard of the
issue (N=22), 96% responded that the reason was because reimbursement rates were low. While it’s difficult to say whether or not lack of provider participation in Medicare is currently creating an access barrier for Medicare patients everywhere, the issue may warrant exploration among the Medicare beneficiary population. When asked if they had heard about endoscopic providers limiting Medicare patients, only 23% of respondents indicated they had heard of the issue. Of those who said yes (N=9), 77% responded that colonoscopy was their state’s primary screening method. Although general awareness of this issue is low, participants who indicated that colonoscopy was their state’s primary screening method had a greater awareness of endoscopic providers limiting Medicare patients than those whose states use FOBT/FIT. Again, the issue may warrant exploration among the Medicare beneficiary population.

Medicaid

The overall awareness of primary care providers limiting Medicaid patients was higher than Medicare; 72% of participants said they had heard of or had experience with the issue. Furthermore, 49% of participants said they had heard of endoscopic providers limiting Medicaid patients, suggesting that the issue of access may be more pronounced among the Medicaid population. When asked the most common reason for primary care providers not taking patients with Medicaid, the overwhelming response was again the low reimbursement rates (93%). Similarly, 95% of respondents who had heard of the issue said low reimbursement was the primary reason for endoscopic providers not accepting Medicaid patients. One aspect of the Affordable Care Act is that states are required to set Medicaid primary care payments relative to Medicare, but only for 2011 and 2012. It may warrant further exploration to see if this was implemented as intended and if it did improve primary care participation within the Medicaid program.

Capacity

In January 2014, the Affordable Care Act expands Medicaid eligibility. Currently, in many states, Medicaid is only available to persons under 65 with dependent children. Under the new eligibility requirements, persons under 65 that are single or married without children and meet the income requirements (133% of the Federal Poverty Level) will be eligible to receive Medicaid. As demonstrated above, there is a general awareness of providers limiting the number of Medicaid patients they will accept. When asked about the Affordable Care Act’s newly eligible Medicaid population, 53% of participants said that insufficient provider capacity will be problematic for screening the Medicaid population, as Medicaid expands.

Recognizing that the roles of primary care and endoscopic providers differ in regards to the CRC screening process, the survey asked whether capacity would be more of an issue for primary care providers or endoscopic providers. Answers to this question were mixed. Forty percent said primary care providers’ capacity would be more of a problem, 18% said endoscopic providers’ capacity would be more of a problem, 25% said they would be equally a problem, and 18% said it would not be a problem.
As mentioned previously, Medicaid coverage varies from state to state and is inherently complex. What will the demand be for coverage once health care reform is implemented, and how will it change CRC screening? It appears that there is uncertainty among Screening Network members on how or if this will be a problem and clearly warrants further study.

Recommendations

Recommendation 1: Address Billing Codes and Classification of a Screening Colonoscopy: Private Insurance and Medicare

Unexpected out-of-pocket costs due to the type of classification of a colonoscopy used when a polyp is found is a current issue that will likely not be solved by health care reform. For private insurance, the type of billing code used determines whether a colonoscopy is classified as a screening or diagnostic/therapeutic procedure when a polyp is found, which potentially increases out-of-pocket costs when considered diagnostic or therapeutic. For Medicare, a screening colonoscopy has no cost sharing for the patient until a polyp is found, which changes the classification to a diagnostic procedure, thus making the patient responsible for co-pays and deductibles. Reforming policies of private insurance and Medicare could affect a large portion of the screening population. This could be achieved through reforming billing code policy on a private level, as South Carolina’s Blue Cross Blue Shield insurance provider has done or with state level policies. On the public side, Medicare cost sharing requirement would likely need to be addressed by federal lawmakers. In addition, once policies are in place, it is important to work with providers to make sure appropriate codes are being used. As previously discussed, the majority of detailed survey participants had heard of the issue and felt the type of billing code used could increase out-of-pocket costs. Additionally, the majority of participants stated that ensuring an endoscopic screen, specifically a colonoscopy, would be classified as preventive rather than diagnostic or therapeutic was the most commonly reported way to lower out-of-pocket costs. This investigation did not uncover if the classification problem was an issue with Medicaid; this is something that should be watched closely among states with waivers around cost sharing, particularly as health care reform is implemented.

Furthermore, this coding/classification issue needs to be explored in regards to FOBT/FIT screening when a follow-up colonoscopy is needed. There needs to be more information gathered on if this procedure can come with unexpected cost sharing. The National Colorectal Cancer Roundtable and the National Colorectal Cancer Screening Network could take an active role in understanding if this type of cost sharing dissuades screening, and educating public health professionals, government officials, and the public about the issue to reform policies and legislation.

Recommendation 2: Implement Worksite wellness policies

Implementing worksite wellness policies, which would encourage employees to be screened and would allow time off from work to be screened, could affect a large portion of the population. Barriers
related to the workplace, such as inability to get time off, will also not be alleviated by health care reform. The majority of Survey 2 participants indicated that their state offered worksite wellness (see Appendix C). The listed worksite wellness activities in Appendix C could be helpful to other states and organizations when implementing change. The National Colorectal Cancer Roundtable and the National Colorectal Cancer Screening Network could take an active role in educating public health professionals, government officials, and the public about current efforts to continue to reform policies and legislation.

Recommendation 3: Public Health policy training

Implementing policy training for public health professionals is essential to achieving systems-level changes. With more policy training, public health professionals will have an improved ability to contribute to reforming policy and legislation on local, state, and national levels. An overarching finding from the project was that generally public health professionals are aware of barriers to screening (e.g. 83% had heard that billing codes could affect a privately insured individual’s out of pocket costs), but that little policy has been enacted to prevent those barriers from occurring (e.g. 5% indicated that a policy had been proposed (not enacted) in their state to prevent this increase of cost due to billing code) The National Colorectal Cancer Roundtable and the National Colorectal Cancer Screening Network could take an active role in educating public health professionals about policy. As previously discussed, the majority of Survey 2 participants said they participated in activities “sometimes” or “often.” However, only half of respondents said they had received training about policy related to CRC screening. The interest in such training was high; 77% reported they would be “somewhat” or “very” interested in such training if offered.

In addition, as noted above Medicaid coverage of colorectal cancer screening is complex and varies by states. As Medicaid expands and insurance exchanges are created by health reform, training for public health workers around coverage could prove beneficial in ensuring that Medicaid and insurance exchange beneficiaries know how to access colorectal cancer screening tests that are covered under the program.

Recommendation 4: Implement a survey of other groups such as medical providers and tribal communities.

Implementing a new survey with medical providers, particularly around public payer reimbursement and capacity issues, could provide new insight into these issues. The composition of our survey population inherently limited the lens through which these issues are seen. For example, providers could provide insight on how frequently primary care or endoscopic providers refuse to accept Medicaid or Medicare patients. If providers are already limiting Medicaid and Medicare patients, the problems of access and capacity will only further be amplified when the Affordable Care Act expands the Medicaid population. Solutions to provide incentives to screen this population will be necessary. Further investigation from the viewpoint of a provider could not only reveal overlooked issues, but could also
foster collaboration and consensus among public health professionals and providers to achieve colorectal cancer screening.

Implementing a survey in tribal communities could also be helpful in understanding the unique barriers in these communities. Tribal communities face unique barriers as Medicare and Medicaid may not be payers in the tribal health system. Additionally, tribal communities differ widely from one another. One participant commented, “In our tribal system all care is provided free of charge...so there are no financial decisions, no reliance on Medicare/Medicaid ... Physician reimbursement rates don't mean anything. Our major concerns are difficulties with encouraging patients to request screening and transportation problems...” The National Colorectal Cancer Roundtable and the National Colorectal Cancer Screening Network could follow-up with another survey to acquire key insight from providers and tribal communities.

Strengths and Limitations

The screening network provided access to public health and medical workers who hear and experience the immediate challenges people encounter in getting CRC screening. However, participation of the network was limited such that all states were not represented. Thus this group, as well as the survey sample, is convenience samples. Some efforts have been made to get to the universe of all current CRC programs, but statistical methods were not used to do this or address this. Additionally, the majority of respondents self-selected into the survey rather than being selected from a random sample. Thus generalization of breadth of knowledge and the need for training is limited. Due to the amount of information we wanted to gather, the survey was nearly 50 questions and took around 20 to 30 minutes to complete; this time commitment could have prevented some people from taking the survey. Having a more representative sample of professions could have yielded different results.

Given the small sample size, most answer choices were limited to exclude an “other” or open-ended response to ensure useful data for analysis. Some participants may have felt that the answers provided did not fully reflect their view; however, due to the fact that key informant interviews were used to create the answer choices, we felt that the answer choices accurately represented the issues in most instances.

As discussed previously, questions concerning Medicare, Medicaid, and cost were not relevant to participants from tribal organizations.
National Colorectal Cancer Network: Overview

WHAT: The Colorectal Cancer Network provides an informal information sharing opportunity for those working in the field of colorectal cancer prevention activities.

WHO: Individuals representing organizations involved in colorectal cancer prevention programming and activities in states, tribes, and territories from across the US. These include: public health professionals (cancer program managers, epidemiologists, community-based organization staff), physicians, nurses, other health care providers, insurance company representatives and others. There is no formal membership and all are welcome to participate if they have an interest in colorectal cancer prevention activities.

WHY: There are often limited opportunities throughout the year to share ideas, best practices and strategies among state, tribe and territorial colleagues working in colorectal cancer prevention activities. The Network meets in order to maximize our time together at professional conferences.

WHEN AND WHERE: Since 2007, we have met before or after scheduled sessions at National conferences such as: National Dialogue for Action, CDC’s Comprehensive Cancer Control Program Director’s Meetings, National Colorectal Cancer Roundtable, CDC’s Colorectal Cancer Control Program annual meeting. In addition, we may have conference calls, webinars and/or electronic communication throughout the year.

HOW CAN I GET INVOLVED IN THE NETWORK? Join us at one of the conferences above for a Network meeting. Details are usually listed on the conference agenda. Provide your contact information to Jennifer Redmond at jredmond@kycancer.org.

The Colorectal Cancer Network is co-facilitated by individuals representing various institutions; however, it functions as a neutral body with no particular agency or organizational ownership.
National Colorectal Cancer Screening Network Survey Results
February 2011

Open: February 17, 2011
Closed: February 28, 2011

This survey was designed to tailor topics for discussion during the National Colorectal Cancer Screening Network meeting at the March 2011 National Dialogue for Action Conference. The survey data regarded network members operating state, sources of funding, meeting topics, etc.

Participants

Participants in the survey (n=85) were recruited from the National Colorectal Cancer Screening Network and represented several primary professions, most commonly health administrators (25%), program coordinators/administrators (21%), and health educators (16%). Thirty-five states, tribes, and territories were represented, with a majority from Nebraska, Maryland, South Carolina, and Tribal organizations. When asked about areas of expertise, most participants (41%) indicated health education, followed by program management/director (23%), medical provider (18%), and advocacy/policy (11%).

Funding Source

The majority of participants (58%) indicated that the CDC’s Colorectal Cancer Control Program was a source of funding for their programs’ colorectal cancer screening initiatives. However, 6% of participants indicated that their state/tribe/territory was not currently funded.

National Dialogue for Action Conference

Almost half of participants (49%) indicated that they would be attending the National Dialogue for Action Conference in March 2011, and participants that were planning on attending were most interested in learning about evaluation of colorectal cancer prevention activities (22%) and policy issues related to prevention/impact of health care reform (20%). Other topics included success stories from prevention activities and public awareness/education.

Challenges

Participants commonly indicated that the two most significant challenges in increasing colorectal cancer screening are limited resources for uninsured, underinsured, underserved (52%) and providers not recommending screening (33%). Public awareness (31%) and patients not wanting screen (25%) were also expressed
as challenges. When asked about programs that were available for screening individuals who are uninsured, underinsured, or considered to have incomes slightly above, at or below FPL standard, 67 participants indicated state funded programs were available, 42 indicated federally funded programs were available, 20 indicated locally funded, and 10 indicated non-profit funded. When examining Medicaid coverage, 66% of participants indicated that Medicaid did provide colorectal cancer screening coverage, 7% indicated that it did not provide coverage, and 27% indicated that they did not know. In regards to the Patient Protection and Affordable Care Act, 26% of participants indicated that their state/program had an implementation plan, 21% of participants indicated that their state/program did not, and 54% did not know. Of the 26% that indicated that their state/program had a plan, only 9% of participants knew if it addressed colorectal cancer screening, while 85% did not know.

Conclusion

Our hope is that these survey results will provide you with information about other Network members and their programs, but also act as resource to increase colorectal cancer screening. If you would like to receive more detailed information about this survey, please contact Keavy McAbee at keavy.mcabee@ucdenver.edu

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Appendix C

Key Informant Interview Guide (March 2011)

Introduction

- Project description: The purpose is to explore issues surrounding state and local practices and policies; medical providers and access to medical care as it relates to colorectal cancer screening
- Partnerships: Project is sponsored by the National Colorectal Cancer Roundtable and will be conducted by the leadership team of the Colorectal Cancer Screening Network
- We are conducting key informant interviews to facilitate the tailoring concise and perceptive survey questions which will be asked of the members of the Colorectal Cancer Screening Network Members and their contacts. This survey will be used to complete our project, through which we aim to provide information to the public, providers and decision makers about national and state policy issues that can help increase colorectal cancer screening
- It is important to conduct these key informant interviews so we know the right survey questions to ask so that we may better understand access to screening.
- Your information (name, place of work) will be kept confidential and all interviews will be analyzed for content and not be associated with your personal information.

Key informant questions:

1. As the (insert title/organization here), what is your role in regards to colorectal cancer screening?
2. What are two or three of the greatest barriers for individuals to receive access to CRC screening (specifically thinking about policies and practices)?
3. What kind of barriers to screening will remain even after health care reform is put into place?
4. What do you think the next steps will be in driving the consumer to be screened?
5. Is there anything else you would like to discuss/share that we haven’t that you feel is relevant?
6. Is there anyone else you think we should talk to?

Outline of Key Informant Interview Results

Current Barriers to Screening

- Public Awareness
- Affordability
  - Uninsured
  - Underinsured
  - Coding: diagnostic v. preventive
  - Cost sharing
  - Hidden costs

Barriers after health care reform
• Affordability
  o Coding: diagnostic v. preventive
  o Medicare loophole: diagnostic v. preventive (cost sharing for diagnostic- when polyp is found)
• Capacity
  o Rural and Urban
  o insurance mandate
  o % Medicaid and Medicare patients that providers accept, especially w/ newly eligible
• Logistics
  o Time off work
  o Transportation

Next Steps

• Systems Change
  o Patient Centered Medical Home
  o Medicaid/Medicare
    ▪ Loophole
    ▪ Reimbursement
  o Insurance
    ▪ Diagnostic v. preventive
    ▪ Coding
    ▪ Transparency in medical costs
• Awareness
  o Public
    ▪ Medicaid grant funding for preventive activities
  o Providers
  o Legislators
    ▪ Cost-benefit analysis
    ▪ Budget
• Communication
  o Provider-specialist
  o Provider-patient
    ▪ EHR reminders
  o Key stakeholders: communication between providers, insurance, advocacy, etc.
Clarifying “Free” Screening Colonoscopies for Medicare Patients

By: Mara Selzer
Supervising Attorney
Elder Law Center
Coalition of Wisconsin Aging Groups
June 2011

On Jan. 1, 2011, the preventative services provision of the Affordable Care Act was extended, making all Medicare patients eligible for free, important preventive services – including colonoscopies. However, not all colonoscopies are created equal, and this could impact whether it is truly without cost to you. This article explains what you should be aware of when receiving this important and life-saving test.

Screening Colonoscopy vs. Diagnostic Colonoscopy

The free Medicare exam only covers screening colonoscopies – not diagnostic colonoscopies. A screening colonoscopy is a procedure performed on a patient of screening age in order to find colon polyps or cancer. A colonoscopy that is performed in order to explain symptoms (e.g. blood in stools, change in bowel movements, etc) is called a diagnostic colonoscopy, which is not covered under the Affordable Care Act. Patients are usually fully liable for at least 20% (and maybe more) of the cost related to a scheduled diagnostic colonoscopy.

There are some cases where a scheduled screening colonoscopy can become a diagnostic colonoscopy, and in those cases a patient becomes responsible for any out-of-pocket costs related to their deductible, co-insurance or co-pays for standard costs like physician and facility fees. A screening colonoscopy becomes a diagnostic colonoscopy when a physician removes a polyp or takes a biopsy during the procedure.

For Medicare patients, a family history of colon cancer or polyps will not automatically transform a screening colonoscopy into a diagnostic one. Some private insurers, however, will do this.

Beware! Related Services Not Always Covered

Medicare patients who are eligible to have a colonoscopy screening will pay no deductible, co-pay or co-insurance.

However, please be forewarned - Patients may still be responsible for other services, such as anesthesia or medication, associated with the procedure. Some of those who have taken advantage of the “free services,” have been unpleasantly surprised to receive hefty bills. If you receive a bill after a “free” Medicare exam, contact the Elderly Benefit Specialist in your county immediately. He or she can help you determine if these charges are allowable.
How often is it covered?

Medicare rules dictate how often you can get a free screening colonoscopy. If you get the test sooner than the time periods listed below, you will likely be fully responsible for the cost.

- **Fecal Occult Blood Test**: Once every 12 months.
- **Flexible Sigmoidoscopy**: Generally, once every 48 months, or 120 months after a previous screening colonoscopy for people not at high risk.
- **Screening Colonoscopy**: Generally once every 120 months (once every 24 months if you're at high risk), or 48 months after a previous flexible sigmoidoscopy.
- **Barium Enema**: Your doctor can decide to use this test instead of a flexible sigmoidoscopy or colonoscopy. This test is covered every 24 months if you are at high risk for colorectal cancer and every 48 months if you aren't at high risk.

How do I qualify?

A Medicare patient can qualify for a screening colonoscopy if they:

- Are of the recommended screening age (for people of average risk = age 50 or over, though recent studies indicate that African-Americans may need to start screening at age 45.)
- Do NOT have any symptoms
- Do NOT have personal history of colon polyps or colon cancer

A Medicare patient can still qualify for a screening colonoscopy despite having:

- A family history of colon cancer or colon polyps

Costs: Screening Colonoscopy

- $0 annual deductible for procedure
- $0 co-insurance for procedure

Costs: Diagnostic Colonoscopy

- $0 annual deductible for procedure
- 20 percent co-insurance must be paid for procedure

Why Should I Get a Screening Colonoscopy?

Colorectal cancer is the third most commonly diagnosed cancer and the third leading cause of cancer death in both men and women in the US. The great majority of these cancers and deaths could be prevented with early screening. This is because most colorectal cancers develop from
adenomatous polyps. Polyps are noncancerous growths in the colon and rectum. Detecting polyps through screening and removing them can actually prevent cancer from occurring. Furthermore, being screened at the recommended frequency improves the chance that colorectal cancer will be detected at an earlier stage, when it is more likely to be cured by surgery alone, the surgical procedure is less extensive, and the recovery is much faster. (statistics excerpted from AMERICAN CANCER SOCIETY, Colorectal Cancer Facts & Figures 2008-2010.)
Response to question 45:

<table>
<thead>
<tr>
<th>State</th>
<th>Worksite Wellness Activities (sorted by State)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alabama</td>
<td>Our roundtable partners are beginning to target the major employers and the state employees’ health care plans to cover CRC screening and become familiar with FIT.</td>
</tr>
<tr>
<td>Alaska</td>
<td>Workplace health promotion program within tribal health system encourages employers to promote all health screenings and education.</td>
</tr>
<tr>
<td>Alaska</td>
<td>Workplace committee working with employers to increase general knowledge of prevention (physical activity, nutrition/obesity, no smoking and screening). Need to show cost benefit.</td>
</tr>
<tr>
<td>Colorado</td>
<td>Prevention Council and Worksite wellness working with large companies to include comprehensive cancer screening support (from time-off for screens, to working with employers insurance carriers)</td>
</tr>
<tr>
<td>Iowa</td>
<td>Offering education to employers and their staff for free education about the need and long term savings of preventive colorectal cancer screenings. Can opt. for a 10-30 minute presentation tacked onto a team/work meeting or a health fair table.</td>
</tr>
<tr>
<td>Kentucky</td>
<td>Colon worksite wellness efforts are underway with KCC and KCP.</td>
</tr>
<tr>
<td>Kentucky</td>
<td>State government employees have essentially no out of pocket costs for preventative services through revision of their insurance provider plan. We are currently engaged with the leadership of metro Louisville on similar issues.</td>
</tr>
<tr>
<td>Kentucky</td>
<td>Comprehensive worksite wellness program training for HR Directors by KY Department for Public Health.</td>
</tr>
<tr>
<td>Michigan</td>
<td>The Michigan Cancer Consortium (MCC) is implementing the MCC Challenge through the CDC cancer policy grant. The Challenge is to the 114 members of the MCC to implement workplace policy change to support cancer screenings.</td>
</tr>
<tr>
<td>Mississippi</td>
<td>On a case by case basis work is being done to get voluntary policies in place to offer paid time off for screening</td>
</tr>
<tr>
<td>Montana</td>
<td>We have local contractors working with organizations to implement policy changes to increase screening rates.</td>
</tr>
<tr>
<td>Nebraska</td>
<td>The NE CCCP is part of a DOH work group focusing on worksite wellness. One of our goals is to increase the number of WW policies that provide time off for prevention and</td>
</tr>
<tr>
<td>State</td>
<td>Description</td>
</tr>
<tr>
<td>--------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Nebraska</td>
<td>wellness councils working with employers</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>Working with major employers to raise awareness about the need for screening, give time off, etc.</td>
</tr>
<tr>
<td>New York</td>
<td>NYS DOH Cancer Services Program, American Cancer Society and others are working with worksites to educate employees about screening.</td>
</tr>
<tr>
<td>Ohio</td>
<td>We have had discussions with industry leaders discussing the value and cost savings benefits of screenings for their workers</td>
</tr>
<tr>
<td>Oregon</td>
<td>Wellness@Work has concentrated on smoking cessation and, to some extent, physical activity and nutrition. Just beginning to branch out to screening.</td>
</tr>
<tr>
<td>Oregon</td>
<td>Our state is working with many worksites (including our own) to establish committees and pass policies to improve health. This includes environmental changes (tobacco-free campus policies, vending machine nutrition standards, etc.) and benefits (including time off for care, etc.)</td>
</tr>
<tr>
<td></td>
<td>See <a href="http://www.healthoregon.org/wellnessatwork">www.healthoregon.org/wellnessatwork</a> for more information</td>
</tr>
<tr>
<td>Rhode Island</td>
<td>A couple of large employers who are self-insured, including one hospital have provided a day off for colonoscopy</td>
</tr>
</tbody>
</table>
Appendix F:

References Consulted


Colorado Area Health Education Center, *Patient Protection and Affordable Care Act (PPACA)*. (2011). AHEC lecture series, Aurora, CO.


University of South Alabama Mitchell Cancer Institute, *Colorectal Cancer Screening: Taking a closer look* (2011).
Acknowledgments

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- Employees of the Colorado Colorectal Screening Program

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