Cancer Screening Reminders: Addressing the Spectrum of Patient Preferences

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ABSTRACT

Context: Health care systems continue to seek evidence about how to optimize the efficiency and effectiveness of cancer screening reminders. Annual reminders to receive preventive services can be an efficient strategy.

Objective: To understand patient motivators and barriers to cancer screening and preferences about reminder strategies.

Design: We conducted 11 focus groups among adults recommended for cancer screening within Kaiser Permanente Washington. We held separate focus groups with women aged 21 to 49 years, women 50 to 75 years, and men 50 to 75 years. We used an inductive, validated coding scheme for analysis.

Main Outcome Measures: Motivators and barriers to obtaining recommended cancer screening and general cancer screening reminder content and modality preferences.

Results: Half of our participants were women aged 50 to 75 years, and 25% were men aged 50 to 75 years. Differences by age, sex, insurance status, financial status, and health beliefs all drove the participants' preferences for whether they seek these recommended services and how and when they wish to be reminded about recommended cancer screening. Most participants preferred personalized reminders, and many favored receiving reminders less than 3 months before the recommended procedure date rather than a consolidated annual reminder. Younger participants more commonly requested electronic reminders, such as texts and e-mails.

Conclusion: Optimizing cancer screening reminders within a health care system involves a multifaceted approach that enables members to request which form of reminder they prefer (eg, electronic, paper, telephone) and the timing with which they want to be reminded, while staying affordable and manageable to the health care system.

INTRODUCTION

Cancer screening remains the best method of detecting breast, cervical, lung, and colorectal cancers to reduce their associated mortality.[1-5] Motivating members to seek appropriate cancer screening requires a strong understanding of the motivators and barriers they face or perceive, which may differ by various factors such as sex, age, and race and ethnicity.[6,7]

Kaiser Permanente (KP) Washington (KPWA) is a mixed-model delivery system that provides health care and health insurance to approximately 650,000 members in Washington State. Before 2007, KPWA (then Group Health Cooperative) mailed separate reminders to members for breast and cervical cancer screenings, timed within a few months of when the screening test was due. Women overdue for the test would receive additional subsequent reminders for their mammogram or Papanicolaou test. After 2007, the preventive care outreach strategy was shifted to a consolidated, annual personalized letter sent around a member's birthday.[8,9] KPWA's annual birthday letter includes a list of all upcoming recommended preventive care services and their corresponding due dates. Each birthday letter includes up to 7 service recommendations tailored to individuals by age, sex, and comorbidities (eg, hemoglobin A_{1C} testing for diabetics). This approach was hypothesized to be more member centered and coordinated than sending individual, test-specific reminders, even if a recommended test was due far off into the future.[10] However, we previously reported important decreases in timely receipt of breast and cervical cancer screening after the transition from reminders with services tied to a due date vs the consolidated birthday reminder.[8,9]

Prior research about cancer screening reminders has predominately focused on how to improve single-service screening uptake,[11-14] with limited attention on the effectiveness of multiservice, consolidated reminders. To better understand the impact of our consolidated outreach strategy on cancer screening rates, we conducted a qualitative investigation to identify member-perceived barriers and motivators to cancer screening and their preferences about how to optimize cancer screening reminders. The goal of these discussions was to improve our understanding of how health system reminders might be leveraged to maximize participation in multiple recommended cancer screenings.

METHODS

Using electronic membership data, we randomly sampled KPWA members in western Washington State by sex and age to align with recommendations for breast, cervical, and colorectal cancer screening. (At the time of these focus groups, lung cancer screening was not yet recommended.) We excluded members enrolled in KPWA for less than one year, because they may not

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have received a birthday letter yet, and members with a known history of cancer, because we felt this population would experience different motivations and barriers for seeking cancer screening. We obtained approval for all procedures from our Human Subjects Research Committee, and all procedures were in accordance with ethical standards.

Care is provided by KPWA Medical Group practitioners in its 25 primary and specialty care clinics. KPWA also serves as an insurer for individuals who receive most or all of their care by practitioners outside the KP system in our network. All our members, regardless of where they seek care, receive birthday letters from KPWA, and all members were eligible for our focus groups.

We mailed invitation letters to potentially eligible individuals in April 2013. For logistical reasons, we preset the dates of the focus groups. The letters included a toll-free number for members to call to volunteer or opt out. A project staff member screened respondents over the phone on a first-come/first-available basis until all groups were sufficiently populated. We scheduled focus groups to take place in the 3 largest regions of our member base: King, Pierce, and Snohomish counties. In each region, we conducted 1 focus group with women aged 21 to 49 years, 2 groups with women age 50 to 75 years, and 1 group with men age 50 to 75 years. Additional groups were conducted with older women (age 50-75 years) because of their eligibility for all 3 types of cancer screening of interest. Focus group times were intentionally varied throughout the day and evening to accommodate participants with different schedules. All 11 focus groups were held in June 2013.

We sampled individuals for our focus groups by age and sex because of the different screening recommendations. In each

Table 1. Description of study participants

Characteristic	Women aged 21 to 49 years, no. (%) (n = 21)	Women aged 50 to 75 years, no. (%) (n = 45)	Men aged 50 to 75 years, no. (%) (n = 24)
Group practice (primary care in KPWA)	12 (57)	33 (73)	17 (71)
High deductible (≥ $500/y)	14 (67)	26 (58)	12 (50)
Race[a]			
American Indian/Alaska Native	0 (0)	0 (0)	1 (4)
Asian	0 (0)	2 (4)	0 (0)
Black/African American	4 (19)	2 (4)	0 (0)
White	12 (57)	35 (78)	16 (67)
Mixed race	0 (0)	1 (2)	0 (0)
Unknown	5 (24)	5 (11)	7 (29)

[a] Race distribution of the participants was only partially known because Kaiser Permanente Washington (KPWA) obtains self-reported race information only from patients who receive all their care in the KPWA system.

Table 2. Participant quotes: Cancer screening motivators

Motivator	Quote
Family history	*"I think for the first mammography, it was [scheduled] because my mom died of cancer and we were all kind of panicky."* [Woman aged 50-75 years]
	"Because my family has a lot of cancer, and it's all different kinds. It would be nice to know which one I'll get. The joke in our family is it's not a matter of if, it's a matter of when and what kind." [Woman aged 50-75 years]
Friends	*"I have a friend who, every year when she goes and gets her mammogram, she posts it on Facebook."* [Woman aged 21-49 years]
	"My fabulous 5 girlfriends I had that I have known since second grade. We always get together, and they start talking about their health issues and 2 of them are nurses, they could not believe that I had never gone in for a full colonoscopy 'til I was 55 … . Peer pressure, yeah, they got to me." [Woman aged 50-75 years]
Stay healthy/believe in prevention	*"It's just an aspect of being healthy and that's probably the most important thing to me. To have a healthy mind, healthy body, and being functionally fit."* [Woman aged 50-75 years]
	"The primary reason [I get screened] is because I know it's in my best interest long term, and if I want to keep what I'm doing in my life, I need to stay healthy. [Man aged 50-75 years]
Practitioner recommendation	*"My doctor recommended it. I didn't really want to take the time to do the colonoscopy, but every year he said you just need to get in here and get it done, so I did, just this last year."* [Man aged 50-75 years]
	"I was trying to think about why I got my first one [Papanicolaou test]. I think just 'cause … the doctor told me to." [Woman aged 21-49 years]
Covered by insurance	*"If I can get anything free, I'm going to do it."* [Woman aged 21-49]
	"I knew you were supposed to have a colonoscopy by 50, I was 49.5. So, I had it because my deductible was paid for, but that was the only reason." [Man aged 50-75 years]
Media/celebrity diagnosis	*"I've been thinking a lot about Angelina Jolie's decision and the publicity it's receiving, and I think that those are really powerful reminders."* [Woman aged 50-75 years]
	"One thing that she [another participant] reminded me of was when Gilda Radner died. That really impacted me. Public figures that you relate to and feel connected to in some way wake you up [to the importance of cancer screening]." [Woman aged 50-75 years]

group, we included members with different insurance plans since costs borne by patients can vary greatly by the member and can play a role in decision making about seeking health care, even in an integrated delivery system. Therefore, some members had low- or no-deductible insurance plans, whereas others had higher annual deductible plans (≥ $500).

Our focus groups included 90 total participants. The same facilitator led all focus groups, each of which lasted approximately 90 minutes. Participants provided written informed consent before the beginning of the discussion. The facilitator used a semistructured guide to ensure consistency between groups but also allowed for relevant spontaneous discussion. The topic areas for the focus group discussions included the following: 1) motivators and barriers to obtaining recommended cancer screening, 2) impressions of the consolidated birthday letter (samples provided), and 3) discussion about general cancer screening reminder content and modality preferences. All focus groups were recorded and subsequently transcribed. Transcripts were coded using an inductive coding scheme developed and validated by the project team. Three team members participated in the coding calibration process by each coding 2 of the same transcripts. Robust agreement was established, which enabled the team to code the remainder of the transcripts individually.

RESULTS

Half of our participants were women aged 50 to 75 years, and 27% were men aged 50 to 75 years (Table 1). The younger women were less likely to receive their care in KP (57%), were more likely have a high-deductible plan (67%), and were less likely to be white (57%) than were the older women and men. Among the older men and women, most (nearly 75%) received their care within KP, and just over 50% had a high-deductible plan. Nearly all focus group participants indicated having had at least 1 prior cancer screening test. Many reported having most or all recommended testing.

Motivators

Participants cited a wide range of motivators for getting screened for cancer (Table 2). Common motivators were often personal, especially knowing someone who had been diagnosed with

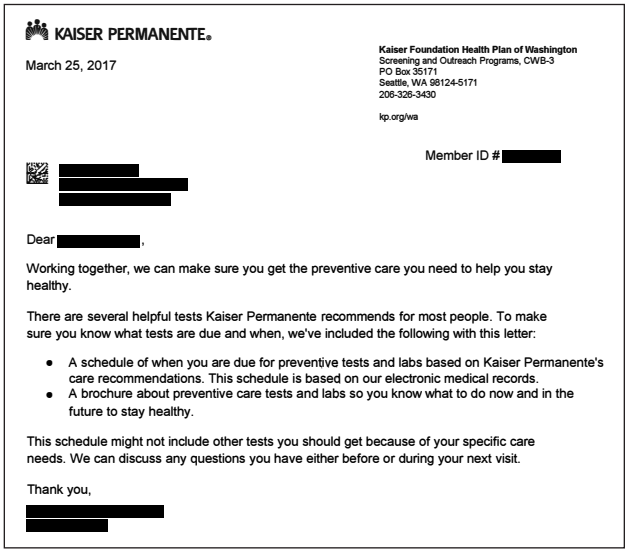
Table 3. Participant quotes: Cancer screening barriers

Barrier	Quote
Cost	*"In my particular plan, we have a high deductible, and so many of the tests require putting money on it. There are some preventive tests that we don't get charged for or that we get some reduced amount for, but it [has] definitely cost us money to have the test done."* [Woman aged 21-49 years] *"They said that if they found some abnormality, like a polyp, it would not be all covered … . Now it's going to cost you money."* [Man aged 50-75 years]
Not at risk	*"I've got no history in my family at all. I mean even my parents are still alive; I just lost my grandparents recently. Pretty long life. Until about 5 years ago, I've usually been in pretty good shape. I exercise every day, but I just haven't felt sick. I just don't get sick. I haven't felt the need [for screening]."* [Man aged 50-75 years] *"Especially someone like me who has no family history. I look at that [reminder] page and say, 'That's a waste of time.'"* [Woman aged 21-49 years]
Procrastination	*"Doctor says I need to do this … . I've got better things to do. I believe he is right. I have faith that he knows what he is doing. I don't know if I'm in avoidance or in denial, but I just kept putting it off, kept putting it off. No physical barrier, just mental attitude."* [Man aged 50-75 years] *"The only thing that I ever resisted was a colonoscopy. I was going to a doctor who had recommended one because of my family history when I was about 47 or 48. I said, 'I feel fine, everything is great, I'm under 50, I eat healthy, I eat pretty healthy,' and I didn't think it was necessary. I absolutely refused to do it. I don't know why I was so stubborn."* [Woman aged 50-75 years]
Fear	*"Nobody wants to be told they have cancer … . I think that's always there."* [Man aged 50-75 years] *"I think you're afraid of what you're going to find out."* [Woman aged 50-75 years]
Pain/discomfort	*"If you're getting screening for colon cancer, a lot of people are put off with the prep."* [Woman aged 50-75 years] *"A doctor recommended a colonoscopy, and I said, 'There's no way.' They were painful back then too, and I heard lots of stories that you really don't want to get that done."* [Woman aged 50-75 years]
Distrust	*"To heck with it, maybe it'll be a false-positive anyway. I just won't do it."* [Woman aged 21-49 years] *"Are you wasting a bunch of money having been poked and prodded for something that would never develop into anything bad?"* [Woman aged 21-49 years]
No time	*"Especially nowadays you can't just get in on the day you want. You have to really think out like 3 months in advance to be able to get in to see someone, and so same kind of idea, 'Well, I don't know what it's going to be like in 3 months, I'll wait.' … It just doesn't get done."* [Woman aged 21-49 years] *"It's hard enough to find time for yourself let alone a buddy to go with ya [for colonoscopy]."* [Woman aged 50-75 years]
Guideline confusion	*"I have heard different doctors say different [recommendations] … about how many years you go between, so I'm very confused about it at this point. First, because of that, I always [went] every 2 years, then every 5 years. I went in this last time and they said 'Oh, 10 years.' I don't know who to trust, basically."* [Woman aged 50-75 years] *"The frequency of when you need to do a mammogram has changed because of fashion or statistics or whatever, but anyway they have different years. Oh, you have to do it every 2 years; oh, you have to do it every year; you have to do it, … and it changes with your age too."* [Woman aged 50-75 years]

cancer or being committed to keeping themselves healthy. KPWA frequently promotes wellness and disease prevention programs, which were cited by some participants as having a positive impact on their motivation to stay well. Others, men in particular, were screened because their health care practitioner or spouse/partner told them to do so. Some participants reported that having the insurance coverage pay for screening was a motivator, or at least conveyed that it removed cost as a barrier. Media stories about celebrities getting screening or having cancer were also reported as impactful motivators.

Barriers

Although most of the participants reported getting some recommended cancer screening, they still expressed concrete or perceived barriers to obtaining it (Table 3). Cost was a concern raised by some participants, especially individuals with high-deductible plans. Some expressed concern about not knowing how much a screening test would cost them personally before undergoing the test. Others were aware their screening test could be free but were concerned about the possible expenses involved in any follow-up diagnostic procedures, for which they knew there were potential deductible charges and copays. Multiple participants reported they did not always get recommended cancer screening because they did not believe they were at risk. They considered themselves to be at low or no risk because they had no family history of cancer and/or were in overall good health. Some participants cited simple procrastination, either based in avoidance or distaste for the procedure. Some of the younger women expressed they could not find time to get cancer screening because of other conflicting responsibilities, such as family or work. Another commonly cited barrier was fear; either fear of the discomfort of the test or fear of the results. More specifically, women cited the pain associated with mammography, and both men and women aged 50 to 75 years reported strong dislike of the preparatory procedures required for having a colonoscopy.



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March 25, 2017

Kaiser Foundation Health Plan of Washington
Screening and Outreach Programs, CWB-3
PO Box 35171
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Member ID #

Dear ,

Working together, we can make sure you get the preventive care you need to help you stay healthy.

There are several helpful tests Kaiser Permanente recommends for most people. To make sure you know what tests are due and when, we've included the following with this letter:

- A schedule of when you are due for preventive tests and labs based on Kaiser Permanente's care recommendations. This schedule is based on our electronic medical records.
- A brochure about preventive care tests and labs so you know what to do now and in the future to stay healthy.

This schedule might not include other tests you should get because of your specific care needs. We can discuss any questions you have either before or during your next visit.

Thank you,

Figure 1. Birthday reminder letter.

Full-text version available at www.thepermanentejournal.org/files/2017/17-051-FullLetter.pdf.

A number of participants voiced distrust about the safety or accuracy of screening tests. At least 1 woman in each of the age 50-plus-years focus groups mentioned reticence to undergo mammography because of the associated radiation. Others harbored distrust having heard stories about poorly conducted colonoscopies that led to patient discomfort or injury. Finally, several individuals across age and sex expressed substantial confusion about screening guidelines, such as historical changes in cervical cancer screening guidelines from annual Papanicolaou test recommendations to longer intervals and changes to breast cancer screening guidelines, particularly for women in their 40s. Many were aware of guideline changes implemented around the time the focus groups were conducted but did not know if or how the changes affected them. Therefore, they cited confusion as a barrier to getting cancer screening, even when screening was explicitly recommended in their birthday letter.

Reminder Preferences

Most women gave positive feedback about the consolidated reminder letter. Some reported they would be motivated to make an appointment after receiving the letter. Many expressed appreciation for the letter because it gave the impression the health care system cares about them and their health. Many participants suggested simplifying and shortening the content to reduce reader fatigue. Participants also suggested including information on how far in advance cancer screening appointments need to be scheduled as well as instructions on how to make appointments online, and providing an online resource for more information on specific tests and procedures. (See Figure 1 for an example letter that incorporates their suggested changes; full-text version available at www.thepermanentejournal.org/files/2017/17-051-FullLetter.pdf.)

Modality Preferences

Each focus group discussed members' reactions to a paper reminder compared with other possible reminder types. Although the mailed reminder still appealed to some participants, many noted they would prefer getting an electronic version instead. Some cited environmental reasons for this preference; others simply wanted to prevent clutter. Still, others felt that eliminating paper could lead to a reduction in their health care costs because they assumed the paper letters were costly for KPWA to produce and mail. Finally, there was a small but vocal subset of mostly older participants (≥ 60 years) who wanted to receive their cancer screening reminders by phone so they could schedule the appointment and ask questions at the same time. They also indicated a phone call was more personal and therefore more appealing to them.

Timing of Reminders

Most participants thought that short-term reminders, which they defined as sent two to three months before a screening test was due, were more effective than annual consolidated reminders. They preferred this timing because it allowed them to make appointments at the time the reminder arrived (many facility and practitioner schedules are not available more than

two to three months in advance) and they were less likely to procrastinate getting the test because it was recommended soon. Participants also preferred test-specific reminders because different cancer screening tests are recommended at different intervals.

A smaller group of participants, who liked to plan further in advance, preferred getting consolidated reminders at a single time each year. Those who voiced this preference felt the lead time of this reminder strategy allowed them to plan long term, even if they were not able to make an appointment immediately for a time when the screening test was due. Some liked the idea of getting obligations (which they considered scheduling their cancer screening to be) planned and checked off their to-do list. Still others considered health care a priority in long-term planning or believed they could budget their finances better by knowing in advance what to expect. Finally, another subset of participants wanted both long-term and short-term reminders.

DISCUSSION

We undertook this qualitative evaluation to understand preferences about individual cancer screening reminders vs member-centered reminders that focus on the whole person instead of specific body parts or systems. Although there is substantial research demonstrating how to increase adherence to preventive services when one is considering a single needed service,[11-14] little research has been done on screening adherence when considering multiple indicated services.[8,9] This qualitative investigation revealed the complexity of making an effective cancer screening reminder system. Differences by age, sex, insurance, and financial status, as well as health beliefs all drove the participants' preferences for how and when they wish to be reminded to obtain recommended cancer screening services and whether they will seek these recommended services. Our findings emphasize the importance of having delivery systems implement multifaceted outreach strategies tailored to member preferences on outreach modality and timing.

Similar to previous studies, many focus group participants, particularly the younger women, wanted direct text or e-mail reminders sent to their mobile device.[15,16] At face value, electronically delivered reminders appear highly feasible. However, a combination of potential technologic challenges and the Privacy Rule, a part of the Health Insurance Portability and Accountability Act regulations that currently prohibits organizations from sending electronic messages directly to members that contain any identifiable health information,[17] would make such text reminders containing health information difficult, if not impossible, to develop and use. KP currently uses secure electronic mail messaging from its patient portal to communicate between patients and their clinical teams; this use may be expanded in the future to include more tailored reminders about preventive services. Importantly, even beyond the feasibility or regulatory environment, electronic reminders will not work for all members, primarily for reasons of it feeling impersonal, lack of Internet access, or low-technology literacy.

Although tailored outreach strategies sound simple, there are many operational challenges to tailoring timing, modality, and content of the reminders. For example, when it came to the content of the reminder itself, participants expressed a preference for being reminded in a relatively brief period before the test was due. However, those preferred time windows likely vary between individuals and require health systems to know detailed risk factors for each person to align the correct screening strategy and interval. There was also a strong desire for reminders to be more personalized with recommendations based on known risk factors, which requires collecting information from members when they enroll in a health care system and continuously keeping that up-to-date. Although such solutions may be technically feasible, there is a high cost associated with such customization.

In addition to preferences on how and when individuals are reminded, other factors played a role in activation and uptake, such as psychological, logistical, and financial barriers. Barriers such as distrust, fear, or not "feeling" at risk were identified as important reasons for avoiding recommended cancer screening. Logistical and financial barriers such as time and cost also played an important role in the participants' decisions whether to obtain recommended cancer screening. There may also be issues specific to certain member subpopulations that health systems should consider. We previously reported results from qualitative focus groups conducted with Latina and black/African American women about their experience and preferences for cancer screening reminders,[18] which highlighted the need to increase the level of knowledge regarding the benefits of preventive care, improve service access through expanded hours or additional clinic locations, and increase cultural competency among the health care professionals who recommend and provide the screening tests.

An important distinction in this work was our focus on understanding how annual preventive services reminders work to motivate individuals to receive recommended cancer screening tests. Most of the literature available regarding cancer screening reminders as well as barriers and motivators is most commonly focused on one test or disease.[19-21] Some of the barriers and motivators cited across age and sex were clearly test-specific, such as a dislike for breast compression during mammography or the arduous nature of the preparation for colonoscopy. But others spanned the horizon of cancer screening in general, such as family history or health beliefs about prevention.

Our focus groups yielded rich member opinions. We acknowledge the sample may have had an overrepresentation of highly motivated members and was also derived from one health care system and one geographic region. Because of logistical reasons, we had to prespecify our focus group dates, times, and locations, which may have also affected who was able to participate. Very few of the people who attended expressed that they had never received any recommended cancer screening. Therefore, these results have limitations to their generalizability. Although we included participants with a wide variety of insurance plans and deductible range, we did not have representation from uninsured populations. Had this population been involved in our discussions, we believe we would have heard that logistics such as transportation, hours of operation, and cost pose an even more prominent barrier

to receiving recommended cancer screening.[22] Finally, we were unable to include participants with limited English proficiency in these groups. Had we been able to do so, we may have also heard about important barriers pertaining to the content of health literature, such as a reminder letter, as well as culturally affected health care-seeking behavior.[23,24] Our study shows that even among an insured population there are important barriers for health care systems to overcome to improve cancer screening rates.

CONCLUSION

Optimization of cancer screening reminders involves a health care system being nimble enough to use a multifaceted approach: One that potentially enables the member to request which reminder modality or media format they prefer (eg, electronic, paper, and/or telephone), and the timing with which they want to be reminded, all while staying affordable and manageable to the health care system. There is likely no one-size-fits-all strategy for cancer screening reminders, and even sending members reminders in their preferred modality will not necessarily translate to increased adherence. But engaging the member preference when determining reminder modality and type warrants further exploration as to whether it might yield higher cancer screening rates and ultimately healthier populations. ❖

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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