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## Partnering to Increase Colorectal Cancer Screening: Perspectives of Community Advisory Board Members

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### Abstract

The Patient-Centered Outcomes Research Institute (PCORI) defines engagement in research as the meaningful involvement of patients, caregivers, clinicians, insurers, and others throughout the entire research process – from planning, to conducting the study, to disseminating study results. The purposes of this paper are to: 1) describe methods used to engage community members across the various phases of a PCORI-funded comparative effectiveness trial to increase colorectal cancer screening; and 2) report results of qualitative and quantitative evaluations of community advisory board members' experiences on this project. Decisions to join and stay engaged with the study included feeling valued and appreciated, being compensated, the opportunity to contribute to research based on their skills and expertise, and being committed to colon cancer prevention efforts. Challenges identified by advisory board members included the significant time commitment, transportation, and meeting location. Lessons learned and guidance for researchers committed to patient and community engagement are described.

### Keywords

patient engagement; community engagement; community advisory board; comparative effectiveness trial; evaluation

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Patients and members of the lay community have become increasingly active partners in research moving well beyond their traditional role as study participants. The Patient-Centered Outcomes Research Institute (PCORI) was established in 2010 as part of the Affordable Care Act and emphasized the engagement of patients and other stakeholders in clinical research (Forsythe et al., 2018). Their unique focus on clinical research has led to inclusion of a specific set of stakeholders, i.e. those who are most proximally

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affected by the research for health decision-making (Frank et al., 2019). PCORI defines engagement in research as “the meaningful involvement of patients, caregivers, clinicians, insurers, and others across the healthcare community throughout the entire research process – from planning the study, to conducting the study, to disseminating study results” (<https://www.pcori.org/engagement/value-engagement>). According to PCORI, the early and continuous engagement of these partners in research is intended to make research more patient-centered, relevant and useful (Clauser, Gayer, Murphy, Majhail, & Baker, 2015). Involving such partners throughout the entire study is expected to lead to greater use and uptake of research results (<https://www.pcori.org/engagement/value-engagement>).

There are six principles of effective engagement that are expected to be integrated into every PCORI-funded project: 1) reciprocal relationships; 2) co-learning; 3) partnerships; 4) transparency; 5) honesty; and 6) trust. *Reciprocal relationships* are demonstrated when the roles and decision-making authority of all research partners are defined collaboratively and clearly stated. *Co-learning* occurs when patients and community members are helped or encouraged to learn about the research process and, in turn, researchers learn about patient-centeredness, engagement and patient and community members perspectives. Genuine *partnerships* are formed when contributions of patients and community members are valued and fairly compensated as well as in reasonable and thoughtful requests for people’s time. *Transparency, honesty* and *trust* are demonstrated when major decisions are made inclusively, information is openly shared, and patients/community members and researchers are committed to open and honest communication (<https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>).

## Purpose

While attention to patient and community engagement has increased, research about engagement in health-related research is limited. Studies describe engagement, but few provide details about how engagement is implemented and systematic evaluations of engagement are lacking (Forsythe et al., 2015). Therefore, the purposes of this paper are to: 1) describe the methods and strategies implemented to engage a diverse community advisory board and the contributions they made to the research; and 2) report results of qualitative and quantitative evaluations of community advisory board members’ experiences on this project.

## Methods

The authors received funding from PCORI in 2016 to conduct a comparative effectiveness trial of two interventions - a mailed digital video disc (DVD) alone and the mailed DVD plus telephone-based patient navigation - to improve colorectal cancer screening among low-income and minority patients served by a safety net hospital system (IHS-1507–31333). This randomized controlled trial focused on recruiting patients who had been referred, and scheduled, for a colonoscopy but did not attend their appointment. On a weekly basis, we received contact information for eligible patients from co-investigators in the endoscopy department. Potential participants were sent a letter and brochure introducing the study and contacted by phone one week later if they did not opt out. Trained recruiters explained the study, answered questions, confirmed eligibility and obtained consent from 433 eligible

patients who were interested. Data were collected by trained telephone interviewers at baseline, 6 months and 9 months after enrollment. Participants were randomized at the end of the baseline interview to receive either: 1) the mailed DVD; 2) the mailed DVD plus telephone-based patient navigation; or 3) usual care. Screening outcomes were extracted from electronic medical records. This trial was designed from the beginning to engage a diverse community advisory board to assist with the implementation of this study and dissemination of results.

### **Formation of the Community Advisory Board**

Prior to submission of the grant application, the research team discussed ways to engage stakeholders and agreed that forming a racially/ethnically diverse community advisory board (CAB) was important. The principal investigator had engaged community members in several prior studies as their input into developing relevant, culturally appropriate, user-friendly and effective interventions to increase colorectal cancer screening was always considered essential (Christy et al., 2013; Rawl et al., 2008, 2012, 2015, 2020; Carter-Harris et al., 2017). With assistance from the Operations Director of the Cancer Center's Office of Community Outreach and Engagement, six potential members of our CAB were identified and invited to attend an informational meeting four months prior to the grant application being submitted. Three had been involved in prior studies conducted by the principal investigator, but all were invited because they either: 1) were a colon cancer survivor; 2) had been a caregiver for a family member with the disease; or 3) received their health care at, or referred patients to, the local safety net hospital where the study was being conducted.

Four months prior to submission of the grant application, a two-hour planning meeting was held where background information about colorectal cancer screening, aims of the proposed study, planned interventions, and outcomes were discussed. Attendees asked questions and provided input on the aims, interventions and outcomes. All agreed the study aims and outcomes were important and appropriate. They were enthusiastic about the potential for the mailed DVD and patient navigation interventions to be well received and helpful. Attendees were particularly supportive of interventions being delivered to participants' homes. Roles and responsibilities of CAB members were described, including the time commitment required and proposed compensation. Attendees were then invited to serve as CAB members on this project and all agreed. One CAB member was invited to serve as a member of the research team in addition to her role on the CAB. This member was employed by a community organization that served low income and minority women whom she referred to our local safety net system for health care services. Because this CAB member also was being compensated as a research team member, she was asked to serve as Chair of the CAB. As chair, she led the CAB meetings in addition to attending all monthly research team meetings. The project manager met with the Chair prior to each CAB meeting to collaboratively prepare agendas.

### **Community Advisory Board Engagement During Project Implementation**

After funding began in 2016, an initial launch meeting was held where CAB members were oriented to the study, their roles and responsibilities, frequency of meetings, and how they would be compensated for their time and contributions. At this meeting, members reviewed

the tailored DVD intervention tested in our prior study that was designed specifically for African Americans (1R01-CA115983; Rawl, PI). Extensive discussion took place regarding the theme, content, messages, actors, charts and visuals that should be kept and deleted as we prepared to revise the DVD, including suggestions for ways to increase its appeal for users of all races/ethnicities. Finally, the schedule for bimonthly CAB meetings to be held during the first year of the project was discussed with consensus reached on days and times that worked best for members. We held all meetings on Tuesdays from 5:30–7:30 pm in a centrally located church meeting room during which dinner was served. During the first year of the study, six CAB meetings were held and during the remaining years, meetings were held on a quarterly basis.

At subsequent CAB meetings, members provided input on numerous aspects of the study. As described earlier, during the first three meetings, members were involved in refinement of the DVD intervention including creating the theme, music, title, and DVD cover design. They also provided guidance on the cultural appropriateness and understandability of the content. When nearing final stages of development, the DVD was pretested with five volunteers; CAB members reviewed and provided feedback on the results of pretesting. The CAB members also provided feedback on the telephone-based patient navigation intervention, expressing the importance of having a nurse to talk to and answer questions in addition to the DVD.

In addition to refining the interventions, CAB members' engagement in developing recruitment materials was invaluable. All members were familiar with the target audience and readily shared their opinions about the readability and comprehensiveness of the recruitment letter sent to potential participants, the study recruitment brochure, the telephone script used when approaching participants, and informed consent procedures. We discussed the planned compensation for participating and all agreed it was reasonable and appealing. CAB members suggested specific types of gift cards that would be most appealing and suggested we offer participants the opportunity to choose between two options.

CAB members were actively engaged in reviewing the instruments being used for data collection. While it was explained that standardized instruments could not be altered, CAB members evaluated all survey items and made recommendations to clarify language and decrease cognitive burden wherever possible. Most of their feedback was relevant to wording of demographic items and simplifying language used by telephone data collectors as they introduced different sections of the interviews.

Another area where CAB members' assistance and guidance were indispensable was in addressing recruitment and retention challenges. Given the nature of this study and the sample being recruited, recruitment challenges were expected, although we were surprised by a higher than anticipated attrition rate. CAB members were actively engaged in generating ideas and making final decisions about solutions to increase recruitment and retention. Retention strategies developed in collaboration with the CAB included designing refrigerator magnets/chip clips with the study logo, office phone number, and tag line "Working Together for Better Health". They suggested we maintain regular contact with participants to keep them engaged between interviews. CAB members regularly contributed

ideas and content for quarterly newsletters that were sent to all study participants to enhance retention. CAB members were featured in newsletters where their photos were shared and their role described. Some contributed a favorite recipe to the newsletter and helped design contests where participants could win gift cards.

Although the study is not yet completed, CAB members have agreed to focus our last two meetings on disseminating study results. They have consistently expressed the need to share the results widely with the lay public and with communities who are disproportionately affected by colorectal cancer, particularly minorities. They will assist with the development of summaries highlighting study results and identify venues to distribute findings. They have already mentioned media (radio, newspapers) that serve minority populations and social media.

Finally, since most CAB members expressed satisfaction with their involvement in this study, we have shared multiple ways that they can continue to engage in research. For instance, two of our CAB members attended the PCORI annual meeting in 2019 which gave them a broad, comprehensive view of patient-oriented research. Every year we share information about scholarships available to attend the PCORI annual meeting which one of our CAB members received. We also invited a guest speaker to one of our CAB meetings who discussed her experience getting involved with PCORI as a peer reviewer of grants and as a patient ambassador.

### **Evaluation of CAB Members' Experiences**

Evaluation of CAB members experience on this project was conducted using both qualitative and quantitative methods. Qualitative data were collected first during a CAB meeting in December 2018 where members were asked a series of questions about their experience serving on the CAB (See Table 1). Questions were shared with members at the quarterly CAB meeting prior to the meeting where this discussion occurred so they had time to consider their responses. Data were collected using a focus group discussion format, led by the principal investigator, and members were not required to participate in the discussion. The discussion, like all CAB meetings, was audio-recorded and responses to all questions discussed were reported verbatim.

Quantitative data subsequently were collected during the fall of 2019 using a survey modified from instruments that were developed to evaluate dimensions of group dynamics within community-based participatory research (Schulz et al., 2003). Schulz and colleagues reported on the development, adaptation, and use of evaluation approaches to assess group dynamics and partnership effectiveness of community-based research partnerships. These authors suggested 73 items to evaluate group dynamic characteristics and 34 items to assess partnership effectiveness. Together, the CAB and the research team reviewed these items and collectively made decisions about items that were most relevant to the experience of being a CAB member on this particular study. Through this process, the number of items was reduced to 43 of the most relevant to minimize the burden for CAB members. Response options for items shown in Table 2 were a 5-point Likert scale where 1=strongly disagree and 5=strongly agree which were dichotomized into agree and disagree for analysis.

Response options for items in Table 3 were on a 3-point scale where 1=not at all and 3=very or a great deal.

Self-administered surveys were mailed to CAB members with a stamped, self-addressed return envelope. CAB members were informed that completing the survey was voluntary and, if willing, asked to complete it anonymously. One CAB member declined to complete the survey. Data were analyzed using descriptive statistics.

## Results

Our CAB originally consisted of eight members, four women and four men. Their average age was 66.4 years, four were married/living with a partner, four were African American, two Hispanic. Five were currently employed, two were retired. One CAB member declined to participate in either phase of data collection and later discontinued his CAB membership due to health issues.

Results of the group discussion are presented in Table 1. Decisions to join the CAB were influenced by feeling valued and appreciated, being compensated for their time, the opportunity to contribute based on their skills and expertise, and being committed to colon cancer prevention efforts. One member stated s/he valued being able to list this CAB membership on her resume. Responses to questions about staying engaged on the CAB reflected: 1) valuing the knowledge gained from participation; 2) having a forum to discuss colorectal cancer with the community; 3) developing and sharing expertise on colorectal cancer screening; 4) being able to socialize; and 5) being part of a team. Two important outcomes mentioned were that serving on the CAB helped one member get a job and motivated another to get screened for the first time. Additional benefits of CAB membership included the personal learning opportunity provided, the ability to make a significant contribution, and enjoying acting in the DVD.

When discussing the challenges of CAB membership, members identified the significant time commitment and meeting location presenting possible safety concerns. Transportation to the meeting was a challenge identified by one CAB member. In response to the question posed about how serving on the CAB could be improved, suggestions included providing support for transportation, considering a different meeting location and having a distance-accessible option to join the meeting. All members agreed they would recommend CAB membership to others because it is a unique learning opportunity that provided personal and professional growth. One member stated, "It is important for community members to understand the research process and being involved would help them understand it better". Members were asked, "Why is it important for people who are not medical researchers to be involved in projects like this?" They responded "being involved allows research teams to have a broad and diverse group of members which is needed to provide different ideas and perspectives" and "to ensure that the final product or results better meet the needs and goals better". Six of seven CAB members stated they would be interested in serving on another CAB for a different research project in the future.

Results of the quantitative survey are presented in Tables 2 and 3. The majority of CAB members agreed or strongly agreed that CAB meetings were useful, well organized, agendas were clear, that all agenda items were adequately addressed and that the CAB had been effective in achieving its goals. They also agreed that the CAB has chosen important problems to work on and they liked the meeting location. Members were very satisfied with the way staff prepared and structured CAB meetings and with the level of follow-up action in response to decisions made by the CAB. Only one member reported wanting more of a voice in determining the agendas. The majority agreed that they increased their knowledge about important topics since joining the CAB, that participating provided personal growth, and that the CAB can have a positive effect on the community.

With regard to group dynamics, most CAB members felt somewhat or very comfortable expressing their opinions at meetings, felt their opinion was listened to and considered by others, and that all members listened to others' points of view, even if they disagreed. Members universally felt they belonged or were part of the group, that everyone on the CAB has a voice in decisions, that good decisions were made, and they were satisfied with the decision-making process. All members felt that there was "some" or "a lot" of openness and trust between CAB members. The majority agreed that certain individuals talked more than others at meetings, but were not bothered by it; only one member stated that one person or group dominated the meetings. The majority indicated that they occasionally suggested new ideas and did not wish to have more input regarding the allocation of resources. Half of the CAB members indicated that, in the past year, their willingness to speak or express their opinion at CAB meetings had increased and half reported it had remained the same.

One open-ended item at the end of the survey asked CAB members to respond to the following question: How could the CAB experience be made more valuable to you? Three responses were: 1) "Cannot think of a thing!! You guys work hard to cross your t's and dot your I's"; 2) "Once the project is completed if the CAB would be able to hold community conversations in areas that served the largest population of each ethnic group in the city to share the findings of the study and distribute literature on the importance of getting tested and proper eating habits/foods to eat to reduce the cause of colon cancer then I'd feel that the time spent on the CAB would be more of value to me and we would have done a great job. I strongly feel that a brief abstract of the project should be shared with doctors in private practice serving majority of minority populations; 3) "I feel that it shall continue like they are. The two awesome ladies, Susan (PI) and Connie (PM) are great and their leadership shows it as, in general, it is amazing and the group was very effective.

## Discussion

Results of this evaluation are consistent with other studies and reviews that examined the perspectives of patients and community members who were engaged in research. Similar to our CAB members, Hemphill et al. (2019) reported that patient and caregiver motivations for engaging in research were primarily related to desires to help improve people's lives or health care experiences, address the needs of underserved populations, have a voice in research, and to learn. Both qualitative and quantitative data supported CAB members'

positive perceptions of their experience with meeting organization, logistics, and CAB group dynamics.

A small number of members identified aspects of the CAB experience that could be improved. These included the need for transportation, concern about the meeting location, and interest in a distance-accessible option to attend meetings. In fact, our March and June meetings in 2020 were held via Zoom and conference calls due to the COVID-19 pandemic. While researchers are both technically expert and comfortable using Zoom for collaboration, several of our CAB members had never engaged with this technology. By providing technical support, education and pretesting, inexperienced CAB members were able to join and actively participate in CAB meetings. These individuals appreciated the assistance they received from staff and were excited when the technology worked, especially during the COVID-19 pandemic. Many CAB members expressed appreciation for being able to see and interact with each other, decreasing the sense of isolation experienced by some. For researchers who plan to engage community members in research, we recommend incorporating resources to provide distance-technology training and support into their studies.

### Lessons Learned

We evaluated our CAB members' experience in the third year of the project leaving little time to make corrections before the study concluded. In future studies, we plan to formalize this evaluation process to implement both formative and summative evaluations on an annual basis with the goal of quality improvement of advisory CAB processes. Luger and colleagues conducted a comprehensive mapping review to help partners identify measures to evaluate community engaged research projects (Luger et al 2020). These investigators identified 28 context measures, 43 process measures to assess concepts such as group dynamics and trust, and 43 measures of impacts and outcomes. They identified significant variation in how community-academic partnerships evaluate domains and recommended future collaborative work to identify a consistent framework for community-engaged research that would enable more systematic measurement of important domains. They also recommended that partnerships include measures throughout the life cycle of the project so that context, processes and outcomes can be assessed.

Engaging patients and community members in research is expected to improve research evidence and health outcomes (Luger et al., 2020) and produce interventions that are relevant and acceptable to the community for which they are intended (Esmail et al., 2015; Frank et al., 2015; Wallerstein & Duran, 2010). Community members can improve the translation of research findings into clinical practice by generating evidence that is tailored to the setting and population (Wallerstein & Duran, 2010; Westfall et al., 2009). In addition, community members can greatly improve dissemination of findings within the community by identifying alternatives to publishing in research journals (Esmail et al., 2015; Forsythe et al., 2015; Isler & Corbie-Smith, 2012; Luger et al., 2020). Perhaps the most important outcome of engaging community members in research is the building of trust and mutual respect between researchers and the lay public, especially for populations underrepresented



in research (Esmail et al., 2015; Frerichs et al., 2017; Getrich et al., 2013; Isler & Corbie-Smith, 2012; Wallerstein & Duran, 2006).

Many researchers are unsure how to engage stakeholders but substantial guidance has been provided by PCORI, seasoned investigators, and the Multi-Stakeholder Engagement Consortium (Concannon et al., 2014, 2018; Sheridan et al., 2017). PCORI's web-based repository of engagement-related tools and resources that were developed and implemented by their awardees may be helpful to investigators who are interested in learning about engaging patients, community members and others in research (<https://www.pcori.org/engagement/engagement-resources>). In addition, PCORI recently launched a free online training course titled *Research Fundamentals: Preparing You to Successfully Contribute to Research* (<https://www.pcori.org/engagement/research-fundamentals#content-6876>). This training provides a self-paced, on-demand set of training modules that use plain language to describe patient-centered outcomes research. The modules are designed to help everyone, regardless of their experience level, engage in research and contribute with confidence. In future studies, we plan to use these online training modules to prepare our community advisory board members and encourage others to consider these useful resources.

While there are multiple ways to engage patients and community members in research, a well-established approach has been to partner with a community advisory board (Newman et al., 2011). CAB members lend their expertise, advice and guidance on important research decisions throughout the entire project (Cramer et al., 2018). Our project benefitted tremendously from the invaluable wisdom shared by our CAB members. We are grateful for their openness, commitment, and dedication over five years to this team and project. We look forward to continuing our collaborations in the future.

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**Table 1.**

## Responses to Qualitative Questions on Community Advisory Board Experience (n=7)

Question	Responses
What made you decide to join the CAB?	Being fed dinner Getting paid for my time Having the opportunity to contribute and do something good based on who I am and the skills and expertise I bring to the team Feeling valued and appreciated Being committed to colon cancer screening and preventing colon cancer Being able to list this on my resume
What kept you coming back?	Joining the CAB helped me get a job The knowledge gained from participating Having a forum to talk to others in my community about colon cancer and cancer in general Developing and sharing my expertise on colorectal cancer and screening Having "street cred" Being able to socialize with others by being a part of a club/team Helped me to meet ladies Motivated me to get screened
What are the benefits/ advantages of being a member of this CAB?	This has been a learning opportunity that I am now able to share with others Has given me the chance to contribute to something significant Getting to act in the DVD was enjoyable
What is difficult about being a member of this CAB?	This is a significant time commitment that has to be integrated into one's life The location of the meeting Possible safety issues Transportation challenges
What can we do to improve your experience?	Provide support for transportation Look into different meeting locations Have a distance-accessible option to join the meeting
Is being involved in research projects like this something you would recommend to other people? If so, why?	All members agreed they would recommend this to others because it is a unique learning opportunity This has allowed me to grow both personally and professionally and could do the same for others It is important for community members to understand the research process and being involved would help them understand better
Why is it important for people who are NOT medical researchers to be involved in projects like this?	Being involved allows research teams to have a broad and diverse group of members which is needed to provide different ideas and perspectives It is important for people who are NOT medical researchers to be involved in projects like this so that the final product or results meet the needs and goals better
Would you be willing/ interested in serving on another CAB for a different research project in the future?	Six of seven CAB members stated they would be interested in serving on another CAB for a different research project in the future.

**Table 2.**

Quantitative Data: Responses to Survey Questions Part 1 (n=7)

Survey Item	Agree (n)	Neutral (n)	Disagree (n)	Mean	S.D.
I find the board meetings useful.	5	1	1	4.00	1.53
I like where our board meetings are held.	6	0	1	3.86	1.34
The board meetings are held too frequently.	0	1	6	4.14	.69
I enjoy attending the board meetings.	6	0	0	4.67	.52
The board meetings are well organized.	6	0	0	4.50	.55
The agendas of the board meetings are clear.	5	0	1	4.00	1.09
The board adequately addresses all of the agenda items at the meetings.	6	0	0	4.17	.41
I would like more of a voice in determining agenda items for meetings.	1	3	1	3.33	1.03
The board has chosen important problems to work on.	6	0	0	4.50	.55
The board has been effective in achieving its goals.	5	2	0	4.14	.90
The board can have a positive effect on the community.	5	1	1	3.86	1.46
I have increased my knowledge about important topics since participating on this board.	5	1	1	4.14	1.57
Participating on this board has provided personal growth for me.	5	1	1	4.00	1.53

**Table 3.**

**Quantitative Data: Responses to Survey Questions Part II**

Survey Item	Not at all (n)	Somewhat (n)	Very/A Great Deal (n)	Mean	SD
How important do you think the work of the board is to the community as a whole?	0	0	6	3.00	.00
How satisfied are you with the level of follow-up action taken by staff in response to decisions made by the board?	0	1	6	2.86	.38
How satisfied are you with the way staff prepare and structure board meetings?	0	1	6	2.86	.38
How much do you feel comfortable about expressing your opinion in the board meetings?	0	2	4	2.67	.52
How much are you willing to listen to others' points of view?	0	1	5	2.83	.41
How much do you feel pressured to go along with decisions of the board even though you might not agree?	5	1	0	2.83	.41
How much do you feel a part of the group (like you belong to the group)?	0	1	5	2.83	.41
How much do you have a sense of ownership over what the group does?	1	3	3	2.29	.76
How much do people on the board feel comfortable expressing their point of view?	0	2	5	2.71	.49
How much do board members listen to each other's' points of view, even if they might disagree?	0	1	6	2.86	.38
How much is your opinion listened to?	0	2	5	2.71	.49
How true is it that everyone on the board has a voice in the decisions?	0	2	5	2.71	.49
How true is it that good decisions are made?	0	2	5	2.71	.49
How satisfied are you with the way the decision-making process is working?	0	1	6	2.86	.38
How much is the board able to make decisions to keep the project moving forward?	0	1	6	2.86	.38