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Facilitating meaningful engagement on community advisory committees in patient-centered outcome research

Gabrielle Kelly, PhD^{1,2}, Shi-Yi Wang, MD, PhD^{1,3}, Georgina Lucas, MSW⁴, Liana Fraenkel, MD⁵, and Cary P. Gross, MD^{3,6}

¹Department of Chronic Disease Epidemiology, Yale University School of Public Health, New Haven, CT

²Center for Social Science Research, University of Cape Town, Cape Town, South Africa

³Cancer Outcomes, Public Policy, and Effectiveness Research (COPPER) Center, Yale Cancer Center and Yale University School of Medicine, New Haven, CT

⁴Robert Wood Johnson Foundation Clinical Scholars Program, Yale University School of Medicine, New Haven, CT

⁵Section of Rheumatology, Department of Internal Medicine, Yale University School of Medicine, New Haven, CT

⁶Section of General Internal Medicine, Department of Internal Medicine, Yale University School of Medicine, New Haven, CT

Abstract

Background—Reflecting on the processes and practices used to engage community stakeholders in patient-centered outcome research strengthens participation at the project level and contributes more broadly to developing knowledge about effective participatory processes and methods.

Objectives—We conducted a process evaluation of ongoing activities of a Patient Advisory Committee (PAC) formed around the development of an individualized decision-aid for older women with early-stage breast cancer.

Methods—In-depth qualitative interviews were conducted with PAC members to obtain their input on the effectiveness of the project's participatory approach and identify barriers to participation.

Results and lessons learned—Although there was general support for the aims of the study, patient knowledge gaps and meeting facilitation style limited participation. Members made suggestions on improving collaboration within the group, that, when implemented, resulted in increased participation and revitalized interest in the project.

Conclusion—Results suggest that engaging committee members in a process of evaluation and collective reflection during a research collaboration can break down barriers to collaboration, build

Corresponding author: Gabrielle Kelly, PhD, Center for Social Science Research, University of Cape Town, 12 University Avenue, Rondebosch 7701, South Africa, Phone number: +27 21 6504656, Fax number: +27 21 6504657, gabby.kelly@uct.ac.za.

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relationships, create opportunities for co-learning and strengthen researchers' capacity to engage meaningfully with stakeholders.

Keywords

PCOR; process evaluation; community advisory committee; participatory research

INTRODUCTION

Because participatory research is still an emerging paradigm in mainstream health research, there remains work to be done in determining what constitutes effective participatory processes and practices, what their impact is on study outcomes, and in refining research methods to make community engagement more successful.^{1–6} Wallerstein and Duran⁷ identify context, group dynamics, community centeredness, and research design as shaping outcomes of community-based participatory research (CBPR). Existing studies and best practice guidelines suggest that successful participatory research requires early initiation of patient involvement, the building of reciprocal and trusting relationships of mutual respect, supportive research staff clear expectations, sufficient reimbursement for participants, flexibility, capacity building and co-learning, and group and self-reflection and feedback.^{2,5,7–9}

The dynamics that emerge within the group is a particularly important factor in project success, but little research has been done in this area.^{10,11} Participatory research relies heavily on interactions between people, but few studies reflect on how participating individuals experience or value research engagement processes.⁹

One way of strengthening collaboration with stakeholders is through process evaluation, a type of evaluation which focuses on operations and implementation.^{3,12–15} Process evaluation presents opportunities for reflection and learning about participatory processes and may also help to clarify the roles and expectations of collaborators. Although relatively few projects conduct evaluations of their own research collaborations,^{1,13–17} existing studies indicate that a commitment to evaluation as a developmental and iterative process is empowering to stakeholders. The evaluation process can improve transparency, reveal potential facilitators and barriers to participation, and improve the robustness of research, helping researchers to gain a better understanding of patient and community interests and priorities.^{2,3,18,19}

This paper presents findings from a small-scale process evaluation of the ongoing activities and processes of a PAC formed to collaborate with researchers on a study involving breast cancer in older women. We conducted a process evaluation to gauge how well the PAC was functioning, identify barriers to participation, and collaboratively find ways to strengthen the relationships between committee members and the research team. We also sought to determine whether the evaluation process itself could be a method of improving collaboration, which can contribute to program learning and change by asking the question: Does engaging with patients around committee processes strengthen the functioning of the committee and improve participation and attendance at committee meetings? By reflecting on these processes, this paper contributes to the limited existing literature on the

implementation dynamics of participatory research projects and provides some guidance to other researchers on improving community engagement practices.

PROJECT AND PARTNERSHIP DESCRIPTION

The objective of the study was to develop an individualized decision aid and risk calculator to help older women (65 and older) with early stage breast cancer make radiation therapy treatment decisions; with the objective being more patient-centered decision making.

To develop a decision aid that is patient centered, meets patients' information needs, and is practically useful to both patients and clinicians, the research team sought to involve community members and clinicians in the process of developing and evaluating this tool over a 5-year period.

Community advisory committees are a commonly used forum for acquiring the input of multiple community stakeholders on the development and implementation of PCOR and well-functioning committees can present an important platform for communication between stakeholders. To this end, a PAC of twelve members and a Clinical Advisory Committee (CAC) of six clinicians were formed at the end of 2014. The CAC includes a medical oncologist, surgical oncologist, radiation oncologist, geriatric oncologist, an internist interested in oncology, and a rheumatologist with expertise in decision science. The PAC (the focus of this article) is composed of community representatives in Connecticut. Twelve individuals were empaneled, including nine representatives affiliated with advocacy, care and support organizations focused on breast cancer, six of whom were breast cancer survivors, and three from organizations focused on geriatric issues. These women were approached based either on their advocacy or personal experience of breast cancer and elder issues, often at the recommendation of the organization they were affiliated with. Strategically selecting stakeholders in terms of their potential contribution to the project has been shown to promote collaboration effectiveness.²⁰ An attempt was made to recruit women representing underserved populations. Four of the members are African American, two are Hispanic, and six are white. The "reputational method" was used to recruit members and proved highly effective.¹⁶ The project team approached organizations that provide healthcare services, support, and resources and act as advocates for older adults and patients with breast cancer. These organizations were asked to recommend staff members, caregivers, or breast cancer survivors who were involved in their activities and whom they felt could act as strong advocates for patients. Based on this referral, potential members were approached by the project team about participating in the committee.

The PAC meets every 2 months for 2 hours at the offices of one of the community partners to discuss the project and provide input. The office is centrally and conveniently located with free parking and provides a neutral (non-university) space for interaction. Members were involved in designing a questionnaire to be used in radiation clinics to establish patient information needs, testing the questionnaire, and reviewing provisional results, and providing input on the decision aid and practicalities of its use. As the project progresses, the committee will also assist to disseminate results, pilot the decision aid, and help advocate for its use. Individuals were also involved in specific tasks such as arranging meetings and

checking the translation of the interview tool into Spanish. To acknowledge their contribution, partners were remunerated for their time and travel expenses. Biannual joint meetings between the CAC and PAC are held to encourage dialogue between these two groups.

RESEARCH METHODS

Because our research was exploratory in nature, a qualitative approach was taken to this study. The evaluation was conducted aft one year of project operations. In-depth interviews or feedback sessions were conducted with 9 of the 12 PAC members in August and September 2015 to gather their views and perspectives on the project's participatory processes and research activities. The feedback sessions also allowed the research associate (RA) to update members who had not been attending meetings regularly on the progress of the project and to clarify any confusion about the project goals. Three members did not participate in interviews for personal or circumstantial reasons.

The interviews were focused on members' motivations for joining the committee and continuing to participate in PAC activities; their expectations of the project and the PAC, and the extent to which these had been met; their understanding of the aims and goals of the project; and their perspectives on the meeting structure and group dynamics (Appendix A). Participants were also asked to make suggestions on areas of research that interested them. As the intention of the project was to gather context- and project-specific information and advice from members for project improvement, in-depth interviews rather than existing trust scales or partnership assessment tools were used, as they provide more space for discussion and building rapport.

These interviews were conducted by the RA rather than the principal investigator (PI) to allow participants space to confidentially communicate their views on how the process was being facilitated. The RA primarily conducted the patient survey in clinics, but was also responsible for making meeting minutes; thus, she routinely attended meetings. However, she only joined the project after members had been recruited and was not involved in the facilitation or planning of meetings and was, therefore, able to take a more objective perspective than other members of the team (PI and CBPR consultant). Nevertheless, her involvement with the project may have shaped member responses to questions and data analysis process in a way that an external evaluator might not have.

Although participants were formally consented for research purposes, efforts were made to keep the interviews as casual, conversational, and relaxed as possible. Interviews were focused on building familiarity and rapport with committee members, as well as gathering feedback. The conversations lasted 60 to 90 minutes and took place over a meal or coffee, with the RA taking almost verbatim notes, using a semistructured interview guide to ensure all topics were discussed. Interview notes, as well as process notes reflecting on the interviews, were summarized by the RA and template analysis was used to identify cross-cutting themes. A priori themes were defined at the outset based on the interview topics and this template was applied to the data and adapted during the analysis process. These themes were discussed within the research team to establish agreement over the analysis. To

strengthen study validity and obtain their input, results of the evaluation were presented to the PAC who provided feedback on provisional findings and discussed ways to implement recommendations.

To determine the effect of the evaluation process on member participation, minutes taken by the RA during meetings and all investigators' notes on and discussions after the five PAC meetings before the evaluation were analyzed and compared with the two after the evaluation.

Ethical approval for this evaluation research was obtained from the Yale University Human Investigation Committee (#1412015066) via an amendment to the original protocol covering the entire project.

KEY INSIGHTS AND LESSONS LEARNED

Recruitment and Community Buy-in

Committee members reported being referred to the PAC by someone they respected—either a colleague or someone in their network—was crucial in securing their participation and trust. Members also felt their professional and personal connections with other members and the opportunity to make new connections in their field were important incentives to participate. Members working with Hispanic and African American communities were motivated to participate by a desire to ensure these undeserved groups were adequately represented on the committee. Whereas practitioners believed participating in the PAC to be an important part of their work, cancer survivors felt it was a way to 'give back' to the breast cancer community and share their experiences.

To secure PAC members' buy-in and for them to feel real ownership of the project, they needed to believe that developing a decision aid was important, would be helpful to patients, and their input would be taken seriously. This was especially important because the research questions and aims were developed by the PI and clinical collaborators before PAC involvement, limiting their involvement in setting the research agenda and potentially undermining their interest in and engagement with the project.¹ Nevertheless, interviews showed that members saw a real need for a decision aid that would help women to understand the risks and benefits of treatment. Their beliefs were based on observations of the confusion and passivity of older women around healthcare information and decisions, or their own personal experiences of cancer treatment that, in some cases, had not been patient centered.

Models of CBPR best practice indicate that it is important for committee members to have a clear idea of the project goals, aims, objectives and processes before they commit to joining a committee.^{6–8} Interview data show that this had not been fully achieved in this project. For example, a number of participants were not entirely clear about the relationship between a patient survey and the decision aid that would be developed, or why the focus of the project was on radiation therapy decision making and not other aspects of care.

I thought it was a project that would help seniors feel more comfortable around their care when they came to Smilow. (Breast cancer survivor and advocate, interview)

The committee member quoted, who had arrived at the first meeting without a clear understanding of the goals of the project, felt disappointed by this limited scope. Although she remained on board out of a sense of commitment, a lack of interest in the project by members may make it difficult to maintain group activities over time. Members who had in-person meetings with the PI before the start of the project had a better overall understanding of the project than those who had not. Our findings demonstrate the importance of sharing project aims and objectives, and providing opportunities for questions and clarification at the recruitment stage.

Communication with Members in and Around Meetings

Regular contact with the group was important to group members and concern for them as individuals—what one member described as “personal touch”—as well as a genuine interest in PCOR—what another described as “authentic sincerity”—was considered by members as important to maintaining their interest and commitment to the project over time. For example, one member did not use email and appreciated efforts to keep her included by mailing her project materials and calling her to remind her about meetings (caregiver and breast cancer advocate, interview). Another member who had breast cancer recurrence and was unable to attend during her treatment strongly valued being kept updated on project activities during her absence and returned after a year, excited to contribute to the group (breast cancer survivor, interview).

Although the size of the project did not warrant monthly meetings, the length of time between meetings (2 months) did result in some members losing track of the project aims and activities.

People tend to forget what the project is about between meetings. (Breast cancer survivor, interview)

Although meeting minutes were sent to all members, several members admitted that they did not always read them, which was especially problematic if they had not attended the previous meeting. Members' confusion and distance from the project demonstrates the need to repeatedly reinforce project goals during meetings, update the committee on progress made, and find ways for them to become more involved in activities between meetings. The interview process provided the opportunity for the RA to clarify the project purpose and goals and the next meeting was dedicated to reminding all members about the project. Based on committee feedback, each meeting now starts with a brief overview of the previous meeting and recent project developments.

Fostering Group Interaction and Participation in Meetings

Regular meeting attendance, which was sometimes as low as 50%, was an area of concern to the investigators. Meetings were held during the week, and times and dates for upcoming meetings were agreed to by the group at every meeting, but cancellations and no shows were still common. Individual interviews established that those who were not attending regularly

remained interested and were equally concerned about their inability to attend meetings because of work or personal commitments. They did, however, express a willingness to use their skills in other ways (e.g., translation or proofreading) and appreciated efforts to keep them up to date and involved by acquiring their input through phone calls, emails, or individual meetings when they were not able to attend.

During interviews, members were able to provide constructive criticism, as well as valuable ideas and insights into the functioning of the group and ideas on how to improve participation. All advisory committee members had prior experience participating in community or expert committees or backgrounds in research or community organizing, allowing them to reflect on their work in the PAC committee in relation to these other experiences. One participant, a former social worker, commented that the research teams' interest in the participatory process led her to believe that the PAC was not just a "box-ticking exercise for grant funding," which had been her experience of other such engagements (breast cancer survivor, interview). Two other members reported that, relative to other project committees, PAC meetings were accessible and communicated at an appropriate level in terms of language and technical knowledge, which was seen as very important:

If the committee is not understanding, how are you going to make others [patients] understand? (Breast cancer survivor and advocate, interview)

Committee members came from a wide range of backgrounds, and had different levels of knowledge about breast cancer and issues related to older people; members generally felt that as a group they were able to collaborate across these differences. However, general observations of group interactions indicated that not all members of the group were equally confident in participating in group discussions and one member described the group dynamic as "a bit tentative and withdrawn" (older person's advocate, interview).

Member feedback also revealed that the structure of meetings (detailed PowerPoint presentations followed by discussion) were not creating the energy the group needed or real opportunities for engagement and dialogue between members. Based on this feedback, meetings were restructured and the research team now spends less time talking and presenting slides to the group and more time facilitating opportunities for dialogue and discussion. Four of the members had significant facilitation experience and agreed to act as a resource to the research team in making meetings more inclusive and participatory. They also agreed to help open up discussion during the meetings.

PAC members are now broken into groups and given particular topics to discuss or tasks to complete and then present their views to the entire group, stimulating further discussion. The move toward small group discussions has proved highly successful in generating participation, and members who had spoken very little during previous meetings for the first time were able to energetically share their opinions and views. This change not only led to more animated discussions and greater input from members, but built relationships between members who had not yet had the opportunity to properly engage. The increase in direct interaction between members reduced the need for the research team to manage discussions and made meetings more egalitarian. Members provided positive feedback after the first

meeting that took into account members' recommendations, indicating that changes made to the new meeting structure were positively received.

Really good interactive meeting today! I think a lot of valuable feedback was brought up about the tool. I really applaud you asking for input. Very interesting project. (Older person's advocate, email correspondence)

Thank you! You are structuring the project in a way that engages participants. (Breast cancer survivor and advocate, email correspondence)

Two members expressed concerns during interviews about the structure of the joint meeting between the CAC and PAC. Although physicians at the meeting were engaging and open to patient input, their professional and research expertise had resulted in them dominating the conversation and the research team engaged more with them than the PAC members. Although not all members agreed, some felt that this meeting simply reinforced traditional, hierarchical relationships between clinicians and patients, and researchers and the community. It was decided that, for these meetings to have value, they need to be facilitated in a way that created opportunities for engagement between these groups and the conversation needed to be pitched at a level that allowed everyone to participate with equal confidence.

Members enjoyed the fact that meetings always focused on a new task or aspect of the project. Seeing the project progress was both a positive sign of their contributions and also maintained interest.

Benefits of the Evaluation Process

The one-on-one interviews were not only valuable in obtaining members' insights, but created a better connection between the research team and members, which was most immediately obvious in the increased attendance (90% at the next meeting) and improved collegiality with the research team. With the exception of weather-related low attendance at the next winter meeting, attendance has averaged 85% at the three subsequent meetings. The evaluation process was also appreciated by members because it represented an acknowledgement of their personal contribution to the committee. The development of individual relationships with members also made it easier for the research team to facilitate discussions within the groups, resulting in increased participation in meetings and improving the dynamic between members. Table 1 presents a summary of key insights on facilitating meaningful participation in advisory committees gathered through this evaluation.

NEXT STEPS

Because radiation therapy is only one part of the breast cancer experience, members were eager to work on other aspects of treatment and shared their ideas for future research during the evaluation process. Moving forward, the project seeks to increase the alignment between community interest and research by engaging the committee on these topics. Several members have also agreed to join the committee for another recently funded and related project, indicating their ongoing interest in collaboration with the research team. To assess the effectiveness of interventions taken in response to partner feedback and continue to learn

from stakeholders, the team will continue to engage in processes of reflection with the committee.

CONCLUSIONS

Achieving meaningful collaboration can be difficult and requires significant commitment to collaborative research principals. As a result, the involvement of patients and communities in advisory committees can remain symbolic or tokenistic and service users and community partners can feel undervalued.^{9,18} To achieve genuine and meaningful engagement with stakeholders, it is imperative that researchers have facilitation skills, understand participatory research principles, and have experience in engaging communities in research. Engaging committee members in a process of reflection can help researchers to strengthen their capacity to engage with stakeholders and creates opportunities for co-learning. Being willing to acknowledge project weakness and learn from it also helps to build more equal and reciprocal relationships, which has been shown as essential in effective participatory research.¹ The results of this evaluation and efforts to implement changes based on PAC feedback offer useful examples of how to strengthen participation and maximize the value of advisory committees to all stakeholders. Evaluating stakeholder engagement and disseminating these results is important in developing standards and improving the quality of patient-centered outcome research more broadly and can enhance the capacity of researchers to conduct this type of research.

Evaluation can also help to identify barriers to stakeholder participation.^{6,21,22} Key barriers identified in this study include the time constraints of committee members, meeting structure and facilitation, and stakeholder confusion about broader project goals and objectives. The latter was largely driven by the lack of an established leadership and agenda-setting role for the PAC. Although this has been corrected somewhat through the evaluation process, the decision making capacity of the group remains limited and must also be balanced against input from the CAC. More work is required to bring these two groups into conversation.

Overall, the study showed that members of advisory committees can provide useful input, not only on research projects, but on improving the functioning and effectiveness of the participatory processes used to seek their input. Engaging with community partners around what is and is not working in participatory research projects and showing a willingness to implement their suggestions strengthens and maintains relationships within advisory committees.¹⁹ It also shows the efficacy of drawing on community partners' own skill sets to strengthen the collaboration, providing opportunities for leadership, which are often limited in such engagements.²³

Although these findings are based on limited evidence and are to some extent context dependent, they do align with existing logic models of CBPR⁷, emphasizing the key role of group dynamics and showing the benefits of reflection, listening, and mutual learning. Adaptations to committee processes aimed at strengthening relationships and building trust also build off these principals. Beside our inability to interview all 12 members, the other main limitation to this evaluation was the lack of member involvement in conceptualizing, designing, and carrying out the process. More research is needed into processes for

evaluation and other forms of group and self-reflection in advisory committees, as well as its potential benefit for group functioning.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1**Key Insights on Facilitating Meaningful Participation in Advisory Committees**

Recruitment and community buy-in	Tap into existing networks for recruitment - Referral to the committee by a trusted source is crucial in securing member participation and trust.
	Create space for networking - Committee members value networking. Opportunities for this should be created within committee meetings.
	Meet with potential committee members in person - Committee members must have a clear idea of the project goals, aims, objectives and processes before they commit to joining a committee.
	Involve committee member in project conceptualization - Interest in and commitment to the project may be limited if members are not involved in this process
Communication in and around meetings	Reach out to those who miss a meeting - Getting the input of members unable to attend meetings and updating them on committee activities is important in sustaining member interest and involvement
	Take a personal interest in members' lives - Building relationships with members as individuals builds loyalty, collegiality and encourages participation.
	Remind members about project details - Project goals, objectives and activities must be repeatedly be re-stated in meetings
Group interaction and participation	Keep it simple - Ensure meetings are accessible in terms of language and technical knowledge
	Ask for feedback - Obtaining members' feedback on committee functioning creates opportunities for co-learning
	Acknowledge and appreciate member input - Show members how you have included their input and where you haven't, explain why.
	Utilize members' skills and experience - Recognizing and using members' individual expertise within project activities shows that their input is valued, deepens involvement and provides opportunity for leadership.
	Create equality in meetings - Attention must be paid to power dynamics between 'experts' and community members
	Make discussion the focus of the meeting - Group work and defined tasks help to build relationships between members and generate more discussion
	Engage with members as individuals - Personal engagement with committee members' builds relationships and may improve attendance at committee meetings
	Keep members interested - Alignment between community interest and research focus helps to maintain stakeholder participation.
Evaluation and learning	Make evaluation a central part of group activities - Showing a willingness to learn and a commitment to making participatory processes effective builds community trust and confidence in the collaboration, increasing participation.