Engaging the Just Right Patient

High Plains Research Network Community Advisory Council
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Abstract -

Context: Engaging patients and community members in research has gained momentum and funding support over the past 2 decades. Long standing participatory research groups may provide a valuable example of patient and community member characteristics associated with successful engagement efforts that are broader than on specific disease and continue beyond an individual project. Objective: Identify patient and community member characteristics associated with successful engaged and participatory research. Study Design and Analysis: Five groups with varying lengths of patient and community member engagement conducted guided conversations about how to identify the “just right” patient for their research engagement efforts. Lists of characteristics were created and refined by the groups. Group lists were compiled, cleaned, and organized around common elements. Setting: The group conversations began with the long-standing Community Advisory Council of the High Plains Research Network in rural Colorado Additional group conversations were held in a rural Montana Community Transformation Training, the Colorado Research Network (CaReNet) Patient Advisory Council, a Boot Camp Translation Facilitator Training, and the NAPCRG Patient and Clinician Engagement (PaCE) Program. Results: Groups identified a broad set of characteristics they believe are necessary and desirable for successful participatory and patient engagement efforts. The groups reported that not everyone must have all of these, but overall, these characteristics are important to long-term relational engagement. Some characteristics are innate, some deal with experience, and others relate to logistical issues. Curiosity, willingness to listen, basic health care knowledge, experience in the community, time to commit to the research activities, ability to travel, no singular personal agenda, sense of humor, a sense of purpose to their engagement work, ability to think outside themselves, put themselves in others’ shoes, ability to speak humbly about their own experience and expertise. Conclusions: Actively engagement community members were able to identify characteristics they believe are important for participatory and patient engaged research. Successful recruitment includes soft skills not just titles, educational credentials or community labels. This requires relationship-based recruitment, relying on extended conversations and interviewing and getting to know one another. Next steps will include identifying the characteristics of the just right researcher.

Character count 2235 (max 2500)

Learning Objectives: After viewing this poster, the reader will be able to:

1) Understand the rationale for considering successful patient and community engagement characteristics.
2) Describe the common characteristics that may be associated with successful patient engaged and community based participatory research.

Research Category
Study Design:
Engaging the Just Right Patient

Background

Engaging patients and community members in research has gained momentum and funding support over the past 2 decades.¹ Multiple funding agencies encourage or require patient engagement in research proposals.² However, there is a continuum of engagement ranging from individual token representation on an occasional advisory group to full community-based participatory research.³ Some organizations engage or hire a patient advisor that advocates for a specific health condition or disease.⁴ Some research groups invite community members to provide one-time or short duration input and consultation.⁵ A growing number of organizations are engaging patients and community members as long-term partners and collaborators.⁶

There are many benefits to engaging patients and community members in research.⁸ Patients provide a fresh voice and can ground discussion in real-life experience.⁹ Patients can help research be more relevant to their community.¹⁰ They challenge the status quo.¹¹ They provide creative ideas for research and clinical quality improvement grounded in personal experience.¹² Many research groups are uncertain about who to engage, and what the work of engagement entails.¹³¹⁴¹⁵ Given that patient engagement is relatively new and there is a broad continuum to genuine engagement activities, the characteristics of patients and community members leading to successful engaged and participatory research has been unclear.¹⁶¹⁷

The High Plains Research Network has successfully engaged community members in all research projects for 20 years.¹⁸¹⁹²⁰ The Community Advisory Council consists of community members and patients with a variety of experience and backgrounds including retired schoolteachers and administrators, farmers, ranchers, small business owners, service providers, and students. As HPRN C.A.C. members attended state and national research meetings they were often asked about their experiences and what makes a good community research partner. Specifically, they were asked about the characteristics of the “just right” patient. Long standing participatory research groups may provide a valuable example of patient and community member characteristics associated with successful engagement efforts that are broader than on specific disease and continue beyond an individual project.²¹

The purpose of this manuscript is to describe the characteristics of the just right patient derived from the engaged patients and community members themselves.

Methods

We conducted facilitated conversations with five patient and community groups. Two groups consisted of community members and patients engaged for 5-10 years as advisors for a practice-based research network. (Colorado Research Network Patient Partners Research Council (CaReNet PPRC)²²²³ and the High Plains Research Network Community Advisory Council (HPRN C.A.C.).²⁴²⁵²⁶ One group consisted of 25 rural hospital leaders and local community members

<table>
<thead>
<tr>
<th>What do engaged patients and community members do?</th>
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<tbody>
<tr>
<td>• Serve as full board member</td>
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<tr>
<td>• Serve on committee</td>
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<tr>
<td>• Present at annual conference/webinar/local symposium</td>
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<tr>
<td>• Provide expertise on the life of a patient</td>
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<td>• Review communications to assure they are understandable to patients</td>
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from 3 communities in rural Montana working on a federally funded physician training program, Montana Team Training for Transformation. The fourth group consisted of 10 researchers and community organizational staff taking Boot Camp Translation Facilitator Training. Derived from the early work of Macaulay et al., the NAPCRG Patient and Clinician Engagement (PaCE) program began as a yearly symposium at the annual NAPCRG meeting. Each year, 40-50 patients, community members, practicing clinicians, and academic researchers participate in a NAPCRG preconference.

Each conversation was 60-90 minutes and asked participants to consider what characteristics were important for patients and community members to possess for successful engagement with researchers; how to identify the “just right” patient for research engagement efforts. Lists of characteristics were created and refined by each group. Group lists were compiled, cleaned, and organized around common elements. The final list was reviewed and agreed upon by the Patient and Clinician Engagement (PaCE) program participants.

Results

The 5 groups identified a broad set of characteristics they believed were necessary and desirable for successful participatory and patient engagement efforts. The groups reported that not everyone must have all these characteristics, but overall, these characteristics were important to long-term relational engagement. Some characteristics were innate, some deal with individual experience and expertise, and others related to logistical issues of participatory engagement.

The long list of characteristics can be found in Table 1. A refined and prioritized list of characteristics can be found in Table 2 and consists of the following priority characteristics: curiosity, willingness to listen, basic health care knowledge, experience in the community, time to commit to the research activities, ability to travel, no singular personal agenda, sense of humor, a sense of purpose to their engagement work, ability to think outside themselves, put themselves in others’ shoes, ability to speak humbly about their own experience and expertise.

The mix of patient and community member characteristics is also crucial. While just one patient in a group is often a “token” presence, sometimes, even one patient’s presence in a group may provide a reminder to everyone of the research goals to improve the life of patients. Other characteristics require a balance. You don’t need all extroverts, probably don’t want all introverts. You need folks who understand when it is time for someone else in the group to talk. And folks who will talk to each other, not just the researchers.

Discussion

Some challenges exist but the art and science of providing education to patients and learning from them will help everyone on the board more fully consider the patient perspective in all of its discussions.
Strength of this manuscript is that the results are derived from patient and community members who are actively participating in a wide range of research activities.

The “just right” patient

These are derived by the engaged patients and community members themselves.

- HPRN Community Advisory Council
- Team Training for Transformation – Montana Community Transformation Training
- Boot Camp Translation Facilitator Training
- CaReNet Patient Advisory Council
- NAPCRG Patient and Clinician Engagement (PaCE) Program

How about a companion piece or a section on Engaging the “just right” researcher.

1
2
4 *Patient Advocates and Researchers as Partners in Cancer Research: A Winning Combination*

Laura D. Porter, Karyn A. Goodman, Josh Mailman, and Wendy S. Garrett
American Society of Clinical Oncology Educational Book 2023 :43
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Laura B Portalupi and others, Developing a patient and family research advisory panel to include people with significant disease, multimorbidity and advanced age, *Family Practice*, Volume 34, Issue 3, 1 June 2017, Pages 364–369, [https://doi.org/10.1093/fampra/cmw138](https://doi.org/10.1093/fampra/cmw138)


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