

Engaging the Just Right Patient

High Plains Research Network Community Advisory Council
Patient And Clinician Engagement (PaCE) NAPCRG

John M Westfall

Maret Felzien

Linda Zittleman

Don Nease

Others

Department of Family Medicine
University of Colorado

Patient And Clinician Engagement
NAPCRG

Word count
Key words

Engaging the Just Right Patient

Title: Engaging the Just Right Patient

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 engaged 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.^{6,7}

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.^{13,14,15} 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.^{16,17}

The High Plains Research Network has successfully engaged community members in all research projects for 20 years.^{18,19,20} 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)^{22,23} and the High Plains Research Network Community Advisory Council (HPRN C.A.C.).^{24,25,26} One group consisted of 25 rural hospital leaders and local community members

What do engaged patients and community members do?

- Serve as full board member
- Serve on committee
- Present at annual conference/webinar/local symposium
- Provide expertise on the life of a patient
- Review communications to assure they are understandable to patients
- more

from 3 communities in rural Montana working on a federally funded physician training program, Montana Team Training for Transformation.²⁷ The fourth group consisted of 10 researchers and community organizational staff taking Boot Camp Translation Facilitator Training.²⁸²⁹³⁰ Derived from the early work of Macaulay et al.³¹, 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.³²³³

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

³ David L Hahn and others, Tokenism in patient engagement, *Family Practice*, Volume 34, Issue 3, 1 June 2017, Pages 290–295, <https://doi.org/10.1093/fampra/cmz097>

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

⁵ Joosten Yvonne A. MPH; Israel, Tiffany L. MSSW; Williams, Neely A. MDiv; Boone, Leslie R. MPH; Schlundt, David G. PhD; Mouton, Charles P. MD, MS; Dittus, Robert S. MD, MPH; Bernard, Gordon R. MD; Wilkins, Consuelo H. MD, MSCI. Community Engagement Studios: A Structured Approach to Obtaining Meaningful Input From Stakeholders to Inform Research. *Academic Medicine* 90(12):p 1646-1650, December 2015. DOI: 10.1097/ACM.0000000000000794

⁶ Romany M. Redman and others, A successful model for longitudinal community-engaged health research: the 2040 Partners for Health Student Program, *Family Practice*, Volume 34, Issue 3, 1 June 2017, Pages 341–346, <https://doi.org/10.1093/fampra/cmz025>

⁷ 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>

⁸

⁹ MacFarlane A¹, Galvin R², O'Sullivan M³, McInerney C⁴, Meagher E³, Burke D³, LeMaster JW⁵. **Participatory methods for research prioritization in primary care: an analysis of the World Café approach in Ireland and the USA.** *Fam Pract*. 2016 Sep 27. pii: cmw104

¹⁰ Ramsden VR, Rabbitskin N, Westfall JM, Felzien M, Braden J, Sand J. Is Knowledge Translation without Patient or Community Engagement Flawed? *Fam Pract*. 2017 Jun 1;34(3):259-261. doi: 10.1093/fampra/cmw114. PMID: 27920121

¹¹ Dember LM. What Patients Teach Us About Patient Engagement in Research. *Clin J Am Soc Nephrol*. 2022 Feb;17(2):176-178. doi: 10.2215/CJN.16561221. PMID: 35131924; PMCID: PMC8823935.

¹² Anjana E Sharma , Kevin Grumbach, Engaging patients in primary care practice transformation: theory, evidence and practice, *Family Practice*, Volume 34, Issue 3, 1 June 2017, Pages 262–267, <https://doi.org/10.1093/fampra/cmw128>

¹³ Ann C Macaulay, Participatory research: What is the history? Has the purpose changed?, *Family Practice*, Volume 34, Issue 3, 1 June 2017, Pages 256–258, <https://doi.org/10.1093/fampra/cmw117>

¹⁴ Kimminau KS, Jernigan C, LeMaster J, Aaronson L, Christopher M, Ahmed S, Boivin A, DeFino M, Greenlee R, Salvalaggio G, Hendricks d, Herbert C, Mabachi N, Macaulay A, Westfall JM, Waitman LR. Patient Engagement vs. Community Engagement: Emerging Issues. *Medical Care* 2018. Oct; 56(10 Suppl 1): S53–S57.

¹⁵ Westfall JM, Zittleman L. Quandaries in Authorship. *Progress in Community Health Partnerships: Research, Education, and Action*, Vol. 12 no. 2, 2018, pp 117-120. Project MUSE, doi:10.1353/cpr.2018.0031

¹⁶ Ramsden V, Salsberg J, Herbert C, Westfall J, LeMaster J, Macaulay AC. **Patient and community oriented research: How is authentic engagement identified in grant applications?** *Canadian Family Physician*. January 2017, vol.63 no.1 74-76. 2017

¹⁷ Zittleman L, Westfall JM. Quandaries in Patient and Community Engagement in Research. Editorial for special issue of *Family Practice: The International Journal for Research in Primary Care*. *Fam Pract*. 2017 Jun 1;34(3):253-255. doi: 10.1093/fampra/cm047. No abstract available. PMID:28525925

¹⁸

¹⁹

²⁰

²¹ Jon Salsberg and others, The shifting dynamics of social roles and project ownership over the lifecycle of a community-based participatory research project, *Family Practice*, Volume 34, Issue 3, 1 June 2017, Pages 305–312, <https://doi.org/10.1093/fampra/cm006>

²² Fisher M, Simpson M, Brewer S, Zittleman L, Westfall JM, O'Leary S, Fernald D, Nederveld A, Nease

DE. Strategies for Developing and Sustaining Practice and Community Advisory Groups: Lessons from the State Networks of Colorado Ambulatory Practices and Partners (SNOCAP) Consortium. Of Practice-Based Research Networks. JABFM 2019. 32(5) 663-673. DOI: <https://doi.org/10.3122/jabfm.2019.05.190038>

²³ Fisher M, Simpson M, Brewer S, O'Leary S, Fernald D, Nederveld A, Holtorp JS, Zittleman L, **Westfall JM**, Nease DE. Process for Setting Research Priorities: A Case Study from the State Networks of Colorado Ambulatory Practices and Partners (SNOCAP) Consortium. JABFM 2019. 32(5) 655-662. DOI: <https://doi.org/10.3122/jabfm.2019.05.190037>

²⁴ Norman N, Cowart S, Felzien M, Haynes C, Hernandez M, Rodriguez MP, Sanchez N, Sanchez S, Winkelman K, Winkelman S, VanVorst R, Zittleman L, **Westfall JM**. Testing to Prevent Colon Cancer: How rural community members took on a community-based intervention. Annals of Family Medicine 2013; 568-570. Doi.10.1370/afm.1586. Supplemental Video: <http://www.annfammed.org/content/11/6/568/suppl/DC1>

²⁵ **Westfall JM**, Felzien M, Zittleman L. Building a mental, emotional, and behavioral health community of solution in rural Colorado. Federal Reserve Bank of San Francisco. Community Development Innovation Review. Mental Health and Community Development. 2018. 13:1 pp 81-90.

²⁶ **Westfall JM**, Zittleman L, Felzien M, Ringel M, Lakin A, Nease D, on behalf of the High Plains Research Network Community Advisory Council. Institutional Review Board Training when Patients and Community Members are Engaged as Researchers. Fam Pract. 2017 Jun 1;34(3):301-304. doi:10.1093/fampra/cmw112. PMID:28525924

²⁷ Team Training for Transformation. **HRSA Primary Care Training and Enhancement Program** <https://www.umt.edu/family-medicine/whowear/grants-and-scholarships/> accessed 5.24.23.

²⁸ Norman N, Bennett C, Cowart S, Felzien M, Flores M, Flores R, Haynes C, Hernandez M, Petra-Rodriguez M, Sanchez N, Sanchez S, Winkelman K, Winkelman S, Zittleman L, **Westfall JM**. Boot Camp Translation: A Method for Building a Community of Solution. Journal of the American Board of Family Medicine 2013. 26: 254-263.

²⁹ Zittleman L, Espinoza A, **Westfall JM**. Boot Camp Translation: Translating complex medical jargon into locally relevant messages and materials. Book chapter in; Zimmerman, Emily, Methods in Stakeholder Engaged Research. March 2020. SAGE Publications, Inc.

³⁰ **Westfall JM**, Zittleman L, Felzien M, Backlund-Jarquín P, Tamez M, Nease D. Reinventing the Wheel of Medical Evidence: How the Boot Camp Translation Process is Making Gains. Health Affairs 2016; 35:4.

³¹ Macaulay AC, Gibson N, Freeman W, Commanda L, McCabe M, Robbins C, Twohig P. For the North American Primary Care Research Group. Participatory Research Maximises Community and Lay Involvement. BMJ 1999;319:774-8

³² Sand J, Felzien M, Haeme R, Tapp H, Derkowski D, **Westfall JM**. The North American Primary Care Research Group's Patient and Clinician Engagement Program (PaCE): Demystifying patient engagement through a dyad model. Fam Pract. 2017 Jun 1;34(3):285-289. doi: 10.1093/fampra/cmz027. PMID: 28407144