



Engagement & Recruitment Tips for Building a New Advisory Board

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This document highlights important considerations and potential best practices in stakeholder engagement, both in general and in long term services & supports (LTSS) settings. It includes suggestions and tips for engaging stakeholders and partners, followed by more specific approaches for LTSS settings and recruitment. Additional resources are listed at the end of this document. **Many of these tips and approaches are also addressed in the virtual seminars for researchers; seminar recordings are available on the Sages in Every Setting [webpage](#).*

The engagement tips listed below are based on CJE SeniorLife's experiences with developing multiple research advisory boards, interviews with stakeholders in the Sages in Every Setting project, and review of existing resources and literature on engaging stakeholders in research.

Engaging Stakeholders

Identifying Partners

Note: Partners are the research organization or group of researchers and the provider organization or group of providers who work together to develop an advisory board (see Elements for Success). This section on engaging stakeholders was written with researchers in mind but it may be helpful for provider organizations to consider a researcher's approach or use the tips if they wish to engage researchers or other provider organizations.

- **Identify the specific type of setting you wish to engage.** Select communities, neighborhoods, residential buildings, or specific organizations that represent the stakeholders you are trying to reach. For the Bureau of Sages, we focused on groups often excluded from research.
- **Identify potential partners with similar values or goals.** Identify groups or organizations who work with the stakeholders you wish to engage. Look at public information and individuals who are familiar with the organization to

determine if the potential partner's values, goals and activities will be a good fit with your engagement goals.

- **Identify potential partners who are likely to be interested in making research useful.** Organizations that are committed to positive change in another area may also see the value of changing how research is done. This may include organizations that value giving voice to their constituency, using evidenced-based interventions, or engaging in continuous quality improvement.
- **Build on prior relationships.** Identify relationships that already exist for other purposes such as internships, service learning, or collaborative projects. These can include connections with key individuals or organizations, participation in community networks, or existing partnerships.

Engaging Partners

- **Demonstrate familiarity with the constituency that partners work with.** Know something about who they serve and what they do.
- **Identify aspects of the setting that could affect partnership building.** Seek to understand and address potential challenges to developing a partnership (e.g., conflicting interests, reasons for resistance to change, differing definitions of key concepts or outcomes). Be familiar with cultural context, racial or ethnic differences, and community histories. Be aware of other issues that impact actors in this setting such as the policy or regulatory context, socioeconomic issues, or other urgent needs in the community or organization.
- **Demonstrate a desire to learn from your partners.** Ask partners to share their knowledge related to their constituency, the setting and the larger economic, political or cultural context. Become familiar with their organizational culture(s). Learn key terms or concepts, values, goals, activities, and desired outcomes. Seek input on the process of developing an advisory board and disseminating its outcomes or product. Ask staff to guide you in how to best do things in their organization (i.e., be sensitive to unstated norms or expectations).
- **Identify and collaborate with gatekeepers and champions for engagement.** Identify individuals within the organization or setting who are connected to and respected by others (i.e. gatekeepers), as well as individuals who have expressed a commitment to including diverse voices in other activities (i.e. champions). Cultivate their trust, interest, and commitment. Seek their advice on how to share your interest in engaging their organization(s) and/or those they serve in research. Partner with them to reach key stakeholder groups.
- **Nurture the partnership process.** Foster and sustain the support of leadership. Establish clear and regular communication mechanisms and feedback loops. Collaborate to develop roles and responsibilities. Identify and address challenges together. Develop MOUs that outline roles, tasks and relationships. Allocate funding in your research budgets for partners, gatekeepers, champions, co-researchers, and other stakeholders. Develop strategies for handling turnover in personnel and stakeholder representation.
- **Share useful knowledge throughout the process.** Share information or research that may be useful to partners. Provide updates on the progress of

studies or plans for research. Share your research results or other products that meet the needs of partners for programming, marketing, quality improvement, outcomes measurement, or strategic planning.

Identifying Individual Stakeholders

- **Identify individuals who can represent diversity within the constituency.** Individuals should represent different perspectives, skills, knowledge, cultures, or experiences. They should demonstrate a desire and/or ability to speak to the interests/needs of others in their group or community. Some may have experiences or “wear multiple hats” that provide more than one source of expertise.
- **Identify individuals who have the capacity to learn and share.** Individuals who are interested in participating in new experiences, talking with new people, making connections with the community, participating in stimulating discussions, contributing something to society, and/or making a difference for the future may be good candidates. Be sensitive to the time and energy their commitment may require, especially for individuals who are overburdened by frequent requests to represent their constituency.
- **Foster or provide incentives to engage.** Work together to ensure engagement is meaningful for all those involved. Compensate involved stakeholders for their time and effort using strategies that are appropriate for their needs and the setting (financial and non-financial).

Engaging Individual Stakeholders

- **Collaborate with them to develop the most effective ways to foster dialogue and meaningful interaction.** Seek their input and regular feedback on engagement formats, groups, strategies, techniques, or technologies.
- **Accommodate their particular needs and preferences.** *Note: A variety of examples of accommodations are provided in the virtual seminars for researchers and in the document “Communication Tips.”*

Specifics for Engagement in LTSS Settings

Engaging Nursing Homes and other LTSS Providers

- **Explore potential benefits for LTSS providers.** Discuss how research/starting an advisory board could benefit the organization. For instance, in reputation or marketing, an advisory board could be indicative of other person-centered high quality programs. Additionally, an empowering activity for residents could help build a more positive culture for everyone at the organization. Show providers tangible examples of projects or events from the CJE [website](#) to demonstrate these effects.
- **Explore LTSS provider challenges.** Be aware of the reasons that providers may not be interested in a bureau. Considerations include cost, either in terms of

technology or time, a culture that does not prioritize client activities, fear of regulations, or lack of continuity in staffing. Be prepared to address these issues, but also be prepared to explore other options if there seem to be too many hesitations.

- **Explore interest and seek input from staff at different levels of the organization.** This includes seeking their input on whether the group could work in their context, how the group would run logistically, the resources it would require to establish/maintain the group, and what might interest the potential members.
- **Learn about the context of long-term care or services.** Be aware of state and federal regulations, requirements, compliance issues, or procedures that could impact engagement. Ask providers for guidance in how to meet any organizational or regulatory requirements for protecting and engaging their residents/clients, including compensating participants (members or staff) for their time and effort.
- **Be sensitive to cultural issues within the organization, community and/or setting.** Gain understanding of the experiences of the specific population(s) being served (e.g., rural, people of color, etc.). Learn about the community the facility serves. Confirm what you know and don't know about the setting and show a desire to learn when engaging diverse stakeholders.

Engaging LTSS Recipients

- **Explore potential benefits of participating as a research advisor or member of an advisory board.** Developing an advisory board can give LTSS recipients a rare opportunity to participate in academic discussions or to advocate for better care. Other possible benefits include the opportunity to build relationships with other members, to feel empowered to speak their mind, and to improve something for others in their position. Avoid confusing jargon or “research-speak” when first reaching out. Keep in mind that family buy-in may be important dependent upon the cognitive status of the participant.
- **Explore their interest in research.** Explore their attitudes about research, including lack of experience. Validate their definitions of and experiences with research of any kind (market research, being a participant in a study, personal health research, etc.).

Recruitment Considerations

- **Be clear but positive about an advisory board's impact.** Potential members may be interested in personal benefits such as finding a cure for their illness or getting better care or services. Their interests and concerns should be validated, along with pointing out how their view could help educate researchers. Members need to be made aware that they will be representing the views of others living with similar conditions or in similar situations, and they may not personally benefit from any particular research. The orientation and research

training are designed to address personal concerns and agendas in a way that can be generalizable to others living in their situation.

- **The size of an advisory board will impact representation, but group size also depends on the capacities of its members for engaging in research training, discussion, and interaction.** Advisory boards that have only a few members may not represent enough diversity in experiences and perspectives, yet a very large board may not allow for all voices to be equally heard in discussions. In our experience, groups of 4-8 have enabled members to build a sense of community with peers and to feel comfortable having non-threatening discussions with researchers, but this is dependent on circumstance.
- **Each advisory board will need to develop recruitment procedures.** The current bureaus recruited members verbally through one-on-one personal invitations from a trusted source or person, either staff at the site or a pre-existing group. Another method of recruitment is through wider marketing within the provider organization, such as flyers, announcements, or presentations. This strategy will allow the group to recruit people who the staff might not originally consider, but have some interest. It can also help the group feel more inviting and inclusive.
- **The language used to describe the idea of an advisory board should fit the constituency.** Start with their interests and explain the engagement opportunity in understandable terms. For instance, nursing home residents may respond best if the advisory board is described as a stimulating group that meets regularly for small group discussion. Some residents may see this as an appealing alternative to large group activities traditionally offered in nursing homes. In the case of the Virtual Senior Center Bureau, members were used to the idea of online classes, so the bureau was listed as a research discussion group on the class calendar. The bureau for people with early stage dementia felt comfortable being part of a support group-style class, and felt that this was another way to learn about their condition from their peers and advocate for people in their situation.

Resources

Defining Engagement and Guiding Principles

What We Mean by Engagement Patient-Centered Outcomes Research Institute

<https://www.pcori.org/engagement/what-we-mean-engagement>

Engagement Rubric Patient-Centered Outcomes Research Institute

<https://www.pcori.org/engagement/what-we-mean-engagement>

Principles of Engagement Northwestern University, Feinberg School of Medicine.
Center for Community Health

<http://www.feinberg.northwestern.edu/sites/cch/docs/CCHPrinciplesofEngagementFinal.pdf>

Community, Patient, and Clinician Engagement in Research: Key Considerations and Frequently Asked Questions Northwestern University, Feinberg School of

- Medicine, Center for Community Health
<http://www.feinberg.northwestern.edu/sites/cch/funding/PCORI.html>
- Concannon, T. W., Fuster, M., Saunders, T., Patel, K., Wong, J. B., Leslie, L. K., & Lau, J. (2014). A systematic review of stakeholder engagement in comparative effectiveness and patient-centered outcomes research. *Journal of general internal medicine*, 29(12), 1692-701.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4242886/>
- Gonzales, R., Handley, M. A., Ackerman, S., & O' sullivan, P. S. (2012). Increasing the translation of evidence into practice policy, and public health improvements: A framework for training health professionals in implementation and dissemination science. *Academic medicine : journal of the Association of American Medical Colleges*, 87(3), 271-8.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3307591/>
- Kelly, G., Wang, S. Y., Lucas, G., Fraenkel, L., & Gross, C. P. (2017). Facilitating Meaningful Engagement on Community Advisory Committees in Patient-Centered Outcome Research. *Progress in community health partnerships : research, education, and action*, 11(3), 243-251.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5679445/>
- Shea, C. M., Young, T. L., Powell, B. J., Rohweder, C., Enga, Z. K., Scott, J. E., Carter-Edwards, L., ... Corbie-Smith, G. (2017). Researcher readiness for participating in community-engaged dissemination and implementation research: a conceptual framework of core competencies. *Translational behavioral medicine*, 7(3), 393-404. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5645278/>

Helpful Resources to Support Engagement

- Compensation Framework & Sample Engagement Plans Patient-Centered Outcomes Research Institute <https://www.pcori.org/engagement/what-we-mean-engagement>
- A Guide to Planning Accessible Meetings (Updated, Digital Version) Independent Living Research Utilization (originally drafted in 1993) National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR award number 90DP0007). <http://www.adahospitality.org/accessible-meetings-events-conferences-guide/book>
- Alliance for Research in Chicagoland Communities Online Resource Directory Alliance for Research in Chicagoland Communities (AARC) www.ARCCresources.net
- Community-Campus Partnerships for Health Online Resource Directory Community-Campus Partnerships for Health (CCPH) <https://www.ccphealth.org/resources/>
- Progress in Community Health Partnerships: Research, Education, & Action (PCHP) National, Peer-Reviewed Journal to Identify and Publicize Model Programs that Use Community Partnerships <https://www.press.jhu.edu/journals/progress-community-health-partnerships-research-education-and-action>
- Castañeda, S. F., Holscher, J., Mumman, M. K., Salgado, H., Keir, K. B., Foster-Fishman, P. G., & Talavera, G. A. (2012). Dimensions of community and organizational readiness for change. *Progress in community health partnerships: research, education, and action*, 6(2), 219-26.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4169887/>

Street Science: Community Knowledge and Environmental Health Justice Jason Corburn, Associate Professor of City & Regional Planning in the College of Environmental Design at UC Berkeley ISBN: 9780262532723 <https://mitpress.mit.edu/books/street-science> Community-Based Participatory Research Karen Hacker, M.D., MPH, Executive Director of the Institute for Community Health SAGE Publications, Inc. ISBN: 9781452205816 <https://us.sagepub.com/en-us/nam/community-based-participatory-research/book237295>

Community-Based Participatory Research Karen Hacker, M.D., MPH, Executive Director of the Institute for Community Health SAGE Publications, Inc. ISBN: 9781452205816 <https://us.sagepub.com/en-us/nam/community-based-participatory-research/book237295>

Paradigm Shift within Research

Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards Sarah Flicker, Robb Travers, Adrian Guta, Sean McDonald, and Aileen Meagher Journal of Urban Health: Bulletin of the New York Academy of Medicine <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2219570/>

Influencing the Culture of Research Patient-Centered Outcomes Research Institute <https://www.pcori.org/engagement/influencing-culture-research> Community Engaged Research and Citizen Science National Institute of Environmental Health Sciences <https://www.niehs.nih.gov/research/supported/translational/community/index.cfm>

The Clinical Trial Is Open. The Elderly Need Not Apply Paula Span, The New York Times <https://www.nytimes.com/2018/04/13/health/elderly-clinical-trials.html>

Engaging Hard to Reach Older Adults

Tamara Backhouse, Andrea Kenkmann, Kathleen Lane, Bridget Penhale, Fiona Poland, Anne Killeit; Older care-home residents as collaborators or advisors in research: a systematic review, Age and Ageing, Volume 45, Issue 3, 1 May 2016, Pages 337–345, <https://doi.org/10.1093/ageing/afv201>

Holroyd-Leduc et al. Giving voice to older adults living with frailty and their family caregivers: engagement of older adults living with frailty in research, health care decision making, and in health policy. Research Involvement and Engagement (2016) 2:23 DOI 10.1186/s40900-016-0038-7 Available at: <https://researchinvolvement.biomedcentral.com/track/pdf/10.1186/s40900-016-0038-7>

Engaging hard-to-reach patients in patient-centered outcomes research. Karen S Kauffman, Susan dosReis, Melissa Ross, Beth Barnet, Eberechukwu Onukwigha, and C Daniel Mullins. Journal of Comparative Effectiveness Research 2013 2:3, 313-324 <https://doi.org/10.2217/cer.13.11>

Levy, Michelle; Holmes, Cheryl; Mendenhall, Amy; and Grube, Whitney () "Engaging rural residents in patient-centered health care research," Patient Experience

Journal: Vol. 4 : Iss. 1 , Article 6. Available at:

<http://pxjournal.org/journal/vol4/iss1/6>

Liljas, A., Walters, K., Jovicic, A., Iliffe, S., Manthorpe, J., Goodman, C., & Kharicha, K. (2017). Strategies to improve engagement of 'hard to reach' older people in research on health promotion: a systematic review. *BMC public health*, 17(1), 349. doi:10.1186/s12889-017-4241-8

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5399821/pdf/12889_2017_Article_4241.pdf

Experiences and Effects of Structurally Involving Residents in the Nursing Home by Means of Participatory Action Research: A Mixed Method Study. Van Malderen, Lien et al. *Journal of the American Medical Directors Association* , Volume 18 , Issue 6 , 495 – 502. doi: 10.1016/j.jamda.2016.12.072

Evolution in Nursing Home Research: Forming Collaborative Groups. *Caring for the Ages*. Arif Nazir, MD, CMD, Cari Levy, MD, CMD, PhD, James Rudolph, MD, and Kathleen Unroe, MD, MHA [https://www.caringfortheages.com/article/S1526-4114\(17\)30092-6/pdf](https://www.caringfortheages.com/article/S1526-4114(17)30092-6/pdf)

Engagement to Support Culturally Competent Research

American Evaluation Association Public Statement on Cultural Competence in Evaluation American Evaluation Association <http://www.eval.org/ccstatement>
Practical Strategies for Culturally Competent Evaluation Centers for Disease Control and Prevention, United States Department of Health and Human Services https://www.cdc.gov/dhdsp/docs/cultural_competence_guide.pdf