



Stakeholder Engagement in Research Resource List

The following list of resources are for researchers interested in engaging older adults, other stakeholders and/or communities in their research process.

This list was initially created for the virtual seminar series offered as part of the Sages in Every Setting project in collaboration with partners from LeadingAge LTSS Center @UMass Boston.

Stakeholder Engagement Definitions 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>

Bureau of Sages at CJE SeniorLife (History, Testimonials, Resources, and News)

CJE SeniorLife, Leonard Schanfield Research Institute

<https://www.cje.net/research-education/bureau-sages>

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>

Stakeholder Engagement Planning

Compensation Framework

Patient-Centered Outcomes Research Institute

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

Sample Engagement Plans

Patient-Centered Outcomes Research Institute

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

This project was funded by the Patient Centered Outcomes Research Institute through a Eugene Washington PCORI Engagement Award (2606-CJE).

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-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-Campus Partnerships for Health Online Resource Directory

Community-Campus Partnerships for Health (CCPH)

<https://www.ccphealth.org/resources/>

Deeply Engaging Patients with a Mix & Match of Methods

Sarah Davis (Associate Director, Center for Patient Partnerships and Clinical Professor, University of Wisconsin Law School) & Nancy Pandhi (Assistant Professor, University of New Mexico Department of Family and Community Medication, with many contributions from Patient Advisors, colleagues, researchers, engagement experts, and research assistants.

<https://www.hipxchange.org/DeeplyEngagingPatients>

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>

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>

Culturally Competent Stakeholder Engagement

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/dhdsdp/docs/cultural_competence_guide.pdf

Engaging Rural Communities Levy, Michelle; Holmes, Cheryl; Mendenhall, Amy; and Grube, Whitney (2017). "Engaging Rural Residents in Patient-Centered Health Care Research," Patient Experience Journal: Vol. 4 : Iss. 1 , Article 6.
<https://pxjournal.org/journal/vol4/iss1/6>

Sample Projects Engaging Diverse Communities

- HAPEER: Home Care Aides Patient Centered Education and Engagement with Research <https://www.pcori.org/research-results/2016/hapeer-home-care-aides-patient-centered-education-and-engagementresearch>
- Pastors 4 PCOR: Engaging Faith Based Communities
<https://www.pcori.org/research-results/2015/pastors-4-pcor-engaging-faith-based-communities>
- Pastors4PCOR Facilitator Training for Research Ministry Ambassadors
<https://www.pcori.org/research-results/2017/pastors4pcor-facilitator-training-research-ministry-ambassadors>
- Partners for Engaging Diverse Communities LTCFocus.org, Shaping Long-Term Care in America Project. Brown University Center for Gerontology and Healthcare Research. Supported, in part, by the National Institute on Aging. The National Resource Center on Native American Aging. Identifying and increasing awareness of evolving Native elder health and social issues to empower Native people to develop community based solutions.
<https://ruralhealth.und.edu/projects/nrcnaa>

Shifting Research Paradigms to Include Stakeholder Engagement

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>

Funders and Organizations

Examples of Funders with Interest in Stakeholder Engagement

- Patient-Centered Outcomes Research Institute (PCORI)
<https://www.pcori.org/funding-opportunities>
- W.K Kellogg Foundation
<https://www.wkkf.org/what-we-do/community-and-civic-engagement>
- National Institutes of Health
<https://grants.nih.gov/grants/guide/pa-files/PA-14-140.html>
- National Institutes of Health
<https://www.nih.gov/research-training/alofus-research-program/funding/all-us-research-program-engagement-partners-ot2>
- Virginia Commonwealth University, Community Engagement
<https://community.vcu.edu/council/community-engagement-grants/>

Examples of Organizations the Promote Stakeholder Engagement

- Patient-Centered Outcomes Research Institute (PCORI)
<https://www.pcori.org/>
- Bureau of Sages
<https://www.cje.net/research-education/bureau-sages>
- The Leading Age Center on LTSS @UMASS Boston
<https://www.leadingage.org/center-applied-research>
- Northwestern Medicine's Center for Community Health Principles of Engagement
<http://www.feinberg.northwestern.edu/sites/cch/docs/CCHPrinciplesofEngagementFinal.pdf>
- Alliance for Research in Chicagoland Communities (ARCC)
<http://www.feinberg.northwestern.edu/sites/cch/research/arcc.html>
Examples of ARCC projects:
Asthma & Food Allergies in Public Schools
<http://pediatrics.aappublications.org/content/early/2014/09/02/peds.2014-0402>
South Asian Community Partnership to Address Heart Disease
<https://www.ncbi.nlm.nih.gov/pubmed/26475629>
Healthy Chicago2.0 <https://vimeo.com/218319435>

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