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Introduction
Compendium of Web-Based Stakeholder Engagement Resources

**Overview**

This compendium of web-based stakeholder engagement resources is intended to serve as a reference for researchers and community partners interested in integrating stakeholder engagement activities in their research projects. It includes a variety of “gray” literature resources available on the internet, such as technical reports or working papers, from both domestic (U.S.) and international sources. This compendium of internet resources is based on a point-in-time web scan (updated as of April 2015) and is not comprehensive.

This document is a result of ongoing work by AcademyHealth to inform and support development of several products related to engagement in research as part of the PCORI Pilot Project Monitoring Services (PCO-PPM0212).

**Resources by Theme**

Resources are organized by five themes based on their target audience and content.

1. **Engaging the Public in Research (for Researchers)**
   Includes guides, tools, and frameworks for researchers that seek to facilitate public participation in research. Also includes training and educational materials, reviews of methods of engagement, specific tools related to public involvement in priority setting, as well as notable examples of forums, advisory groups, and networks actively engaging stakeholders.

2. **Getting Involved with Research (for the Public/Stakeholders)**
   Includes guides, handbooks, and training materials to support public involvement in research; many of these resources are written in accessible language and formatted for distribution to the public/stakeholders. Also includes searchable websites that allow for patients and other stakeholders to find research projects of interest.

3. **Community-University Partnerships**
   Includes links to websites of notable partnerships between universities and community-based organizations working to ensure that ongoing research is relevant to their communities. Community-based partners may include neighborhood associations, local health systems and clinics, city government and public schools, faith communities, arts and cultural institutions, businesses, and other academic partners.

4. **Patient Involvement in Health Care**
   Resources intended to assist patients in taking an active role in their health, including accessing healthcare, communicating with providers, interpreting medical tests/diagnostics, understanding available treatments, and accessing support options (e.g., interacting with community health workers and counselors).

5. **Community-Based Participatory Research (CBPR)**
   Resources that provide a general definition and review of principles for CBPR, as well as training materials and guidance to support researchers and other stakeholders involved in CBPR.
Compendium of Web-Based Stakeholder Engagement Resources

Resources are presented in lists, and organized by resource type (e.g., handbook, framework, training, etc.). Hyperlinks to all resources are included.

Next Steps

This compendium is intended to be a dynamic resource, and will be periodically updated. We welcome input and suggestions for additional resources that should be included in the inventory, particularly those that may evolve from the work of PCORI funded research efforts. Please contact Laura Esmail (laura.esmail@academyhealth.org) to suggest additional resources for this document or provide other feedback.
Resources by Theme
Theme 1: Engaging the Public in Research (for Researchers)

- **Frameworks/Principles**
  - CDC - Principles of Community Engagement: Guide from the CDC Agency for Toxic Substances & Disease Registry
  - NIH COPR - Definitions of Public Participation and Community Engagement
  - NIH COPR - Community Engagement in Research: Frameworks for Education and Peer Review
  - NIH COPR - Community Engagement Framework for Development of Education/Training for Researchers
  - CIHR - CIHR’s Framework for Citizen Engagement
  - CIHR - Citizen Engagement Handbook Decision Tree Model
  - CIHR - Strategy for Patient-Oriented Research - Patient Engagement Framework

- **General Guides/Handbooks**
  - AHRQ Community Forum - Supporting Patient & Consumer Involvement in PCOR Workshop
    - Workshop
    - Webinar
  - AHRQ EHC - Learning Modules: Engaging Stakeholders in the Effective Health Care Program
  - AHRQ EHC - Innovations in Stakeholder Engagement Conference
  - INVOLVE UK - Resource for Researchers: How to involve members of the public in research
  - INVOLVE UK - Putting it into Practice Database
  - INVOLVE UK - Tips sheet: Recruiting members of the public to get involved in research funding and commissioning processes
  - UCSF CTSI - Community-Engaged Research: A Quick-Start Guide for Researchers
  - UCSF CTSI - Community-Engaged Research with Community-Based Organizations: A Resource Manual for UCSF Researchers
  - UCSF CTSI - Community-Engaged Research with Community-Based Clinicians: A Resource Manual for Researchers
  - UCSF CTSI - Work with Community FAQ
  - UCSF CTSI - An Introduction to Effectiveness, Dissemination and Implementation Research
  - CIHR - Citizen Engagement Handbook

- **Methods**
  - AHRQ EHC - Innovative Methods in Stakeholder Engagement: An Environmental Scan
  - AHRQ EHC - Multi-Criteria Decision Analysis Techniques to Integrate Stakeholder Preferences in Comparative Effectiveness Research
  - AHRQ EHC - Using Deliberative Methods to Engage Patients, Consumers, and the Public
    - Slide Presentation
    - Webinar: How to Design & Implement an Effective Deliberation Session
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- **Priority Setting**
  - AHRQ EHC - [Engaging Stakeholders to Identify and Prioritize Topics for Future Research](#)
  - AHRQ EHC - [Methods Guide for Comparative Effectiveness Reviews - Developing and Selecting Topic Nominations for Systematic Reviews](#)
  - CAPSMG - [Cochrane Agenda and Priority Setting Methods Group](#)

- **Tools/Templates**
  - UCSF CTSI - [Templates for Documents Used in Community-Engaged Research](#)
  - The Voice - [Planning Software for Community Engagement](#)
    - User Guide
    - Key Questions & Handy Hints
    - Finding your VOICE
    - National Standards/VOiCE sitemap

- **Training/Education**
  - AHRQ EHC - [The Facilitation Primer: Strategies, Tools and Resources to Get You Started](#)
  - INVOLVE UK - [Developing Training & Support Resource](#)
  - NIH COPR - [Community Engagement Framework for Development of Education/Training for Researchers](#)
  - Cochrane Agenda and Priority Setting Methods Group
  - AHRQ EHC - [Methods Guide for Comparative Effectiveness Reviews - Developing and Selecting Topic Nominations for Systematic Reviews](#)

- **Evaluation**
  - Lind Alliance - [Scoping research priority setting, and the presence of patient and public involvement, with UK clinical research organizations and funders](#)

- **Forums/Advisory Groups**
  - CMTP - [Patient and Consumer Advisory Council](#)

- **Consulting Services**
  - INVOLVE UK - [NIHR Research Design Service (RDS)](#) support for public involvement
  - CCBR - [Creative solutions to community challenges](#)

- **Networks**
  - InvoNET - network of people working to advance public involvement in NHS public health & social care research (researchers, funders, service users, careers)
Compendium of Web-Based Stakeholder Engagement Resources

- **People in Research** - searchable database of research orgs. & opportunities for public involvement

**Reference**
- INVOLVE UK - [Research Project Database](#)
- NHS (UK) - [DUETs](#) (Database of Uncertainties about the Effects of Treatments)
- UCSF CTSI - [Community-Engaged Research Articles, Reports, and Books](#)
- UCSF CTSI - [Community-Engaged Research Presentations](#)
- UCSF CTSI - [Tools for Best Practice of Community-Engaged Research](#)
- CMTP - [List of staff publications](#) related to stakeholder engagement
- CIHR - [Citizen Engagement in Health Casebook](#)
Theme 2: Getting Involved with Research (for the Public/Stakeholders)

- **Frameworks/Principles**
  - Lind Alliance - Systematic map of studies of patients’ and clinicians’ research priorities
  - NIH COPR - Definitions of Public Participation and Community Engagement

- **Guides/Handbooks**
  - AHRQ - How To Get Involved in the Effective Health Care Program: A Concise Guide for Stakeholders
  - UCSF CTSI - Community-Engaged Research: A Quick-Start Guide for Community-Based Organizations
  - UCSF CTSI - Community-Engaged Research with UCSF Researchers: A Resource Manual for Community-Based Organizations
  - UCSF CTSI - Community-Engaged Research: A Quick-Start Guide for Community-Based Clinicians
  - UCSF CTSI - Community-Engaged Research with UCSF Researchers: A Resource Manual for Community Clinicians
  - Lind Alliance - Guidebook for Priority Setting Partnerships

- **Training/Education**
  - UCSF CTSI - Research & Evaluation Training for Community-Based Organizations
  - UCSF CTSI - Dissemination Training
  - UCSF CTSI - Certificate Program in Implementation and Dissemination Science
  - UCSF CTSI - Community Engagement & Health Policy Program (CE&HP)

- **Methods**
  - Lind Alliance - Setting priorities for treatment uncertainties - a review of methods
  - Lind Alliance - Web review of the Topic Specific Research Networks
  - Joint Campbell-Cochrane Colloquium - Agenda setting: Evidence & Equity
  - Yale CARE - Beyond Scientific Publication: Strategies for Disseminating Research Findings

- **Forums**
  - AHRQ Community Forum
  - UCSF CTSI - Open forums on CER/PCOR
  - NHGRI – Community Genetics Forum

- **Networks**
  - InvoNET - network of people working to advance public involvement in NHS public health & social care research (researchers, funders, service users, carers)
  - CIHR - Synapse Youth Connection

- **Consulting Services**
  - USCF CTSI - Linkage Service in Community Engagement & Health Policy
Compendium of Web-Based Stakeholder Engagement Resources

• Opportunities for Engagement
  o AHRQ EHC - EBC Challenge
  o AHRQ EHC - Get Involved
  o People in Research - searchable database of research orgs. & opportunities for public involvement
  o USCF CTSI - San Francisco Bay Area Collaborative Research Network (SF Bay CRN)
  o CIHR - Institute Advisory Boards (IAB)
  o CIHR - Café Scientifique
  o CIHR - Community Reviewers: Involving the Canadian Public in the CIHR Peer Review Committees

• Reference
  o AHRQ EHC - Research Summaries for Consumers, Clinicians, and Policymakers
  o INVOLVE UK - Jargon Buster Glossary of Terms
  o INVOLVE UK - Evidence Library
  o INVOLVE UK - Research Project Database
  o Lind Alliance - Bibliography of research reports
  o NHS DUETS (Database of Uncertainties about the Effects of Treatments)

Theme 3: Community-University Partnerships

• UCSF CTSI - University-Community Partnerships
• SFHIP - San Francisco Health Improvement Partnerships
• CCEHRS - The Center for Community Health Education Research and Service
• Yale CARE - Yale Community Alliance for Research & Engagement (CARE)
  o Principles and Guidelines for Research Partnerships Executive Summary
  o Principles and Guidelines for Community-University Research
• UVic OCBR - University of Victoria Office of Community-Based Research
Theme 4: Patient Involvement in Health Care

- **Frameworks**
  - CFAH - [Engagement Behavior Framework](#)
  - NeHC – [Patient Engagement Framework](#)

- **Guides/Handbooks**
  - CFAH - [Snapshot of People’s Engagement in their Health Care](#)
  - CFAH - [Supporting Patient Engagement in the Patient-Centered Medical Home](#)
  - CFAH - [Supporting Patients’ Engagement in Their Health and Health Care](#)
  - CFAH - [Engaging Disadvantaged Older People in Their Health and Health Care](#)
  - NAPP - [Community Voices and Starter Guide for Virtual PPGs](#)
  - NAPP - [Getting Started Guide to Starting a PPG](#)
  - NAPP - [Smart guides to engagement - Practices and patient engagement](#)
  - NHS (UK) - [Patient Involvement Toolkit](#)

- **Consulting Services**
  - NAPP – [Consultancy](#)

- **Evaluation**
  - Picker Institute - [The quality of patient engagement and involvement in primary care](#)
  - Picker Institute - [Engaging patients in their healthcare: how is the UK doing relative to other countries?](#)
  - Picker Institute - [How engaged are people in their health care?](#)

- **Training/Education**
  - Picker Institute - [Education for Partnership](#)

- **Forums**
  - CFAH - [Prepared Patient Forum](#)
  - The Patient’s Voice – Medical market research forum(UK)

- **Reference**
  - NAPP – [PPG Case Studies](#)
Theme 5: Community-Based Participatory Research

- **Frameworks/Principles**
  - CCPH - CBPR Principles
  - CCPH – Definitions, Rationale and Key Principles in CBPR

- **Guides/Handbooks**
  - CCPH - Resources to Advance Community-Based Participatory Research
  - CCPH - Examining Community-Institutional Partnerships for Prevention Research
    - Project Fact Sheet
    - Peer-Review Findings
  - CBRC – Community-Based Research Booklet Series
    - What is CBR?
    - CBR & Partnerships
    - Creative Methods in CBR
    - Why CBR Matters
  - UNC/CEAL - Manual for Community-Based Participatory Research: Using Research to Improve Practice and Inform Policy in Assisted Living

- **Ethics**
  - CCPH - Community-Based Participatory Research and Research Ethics
  - CCPH - Understanding Community-Based Processes for Research Ethics Review

- **Training/Education**
  - CCPH - Community Partner Peer Mentoring & Advocacy
  - CCPH - Community-Based Participatory Research Syllabi and Course Materials
  - CCPH - Curriculum Training Module for Developing and Sustaining Community-Based Participatory Research Partnerships
  - CCPH - Developing and sustaining community-university partnerships for health research: Infrastructure requirements

- **Tools/Templates**
  - UCSF CTSI - Review Criteria and Rating Scale for CBPR
  - CCPH - Templates for Documents Used in Community-Engaged Research

- **Networks**
  - CCPH - Online membership directory
  - CCPH - Listservs

- **Consulting Services**
  - CCPH - Consultancy Network - training & technical assistance
  - CCPH - Community Partner Peer Mentoring & Advocacy

- **Reference**
  - CCPH - Publications