

Community, Patient, and Clinician Engagement in Research: Key Considerations and Frequently Asked Questions

Introduction

Academic institutions, government and private funders, researchers, and communities are increasingly recognizing the benefits of engaging patients, caregivers, health care providers, community- and faith-based organizations, community residents, and policymakers in research. Engagement offers a promising approach for ensuring the research and interventions are culturally sensitive and responsive to community needs, as well as increasing the likelihood of generating meaningful and sustainable results. Engagement can also improve research outcomes by helping to avoid common pitfalls that can cause projects to fail (e.g. low enrollment, low intervention fidelity, etc.). Increasingly, engagement is recognized as necessary for translating existing research to implement and sustain new health promotion programs, change clinical practice, improve population health, and reduce health disparities.

This document provides a series of key considerations related to incorporating engagement into different phases of a research project: (1) Getting Started, (2) Implementation, (3) Dissemination. These key considerations are intended to be useful regardless of the type and amount of engagement a research project uses. The document is also intended to be a resource for researchers who are preparing grant applications that require or suggest patient/community/stakeholder engagement. Addressing these key considerations in grant applications illustrates an understanding of fundamental issues related to engagement that are emphasized by reviewers/study sections.

We encourage you to follow-up with staff or faculty at Northwestern University's Center for Community Health for clarification on any of the recommendations found in this document, or for consultation on how to put these recommendations into practice. You may also find some useful resources on the websites below.

Contacts:

Center for Community Health: <http://www.feinberg.northwestern.edu/sites/cch/>,
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Why consider community, patient, or stakeholder engagement in our research?

Engaging communities, patients, and stakeholders can take time and may be unfamiliar to some researchers. Generally, benefits of engagement in research include:

- Facilitating research on issues involving health disparities benefit from patient, community, and stakeholder perspectives
- Developing culturally acceptable strategies for research design and implementation, including recruitment and retention of research participants

- Increased trust generated through engagement may mitigate wariness of populations who remain suspicious of research, university researchers, or healthcare systems
- Collaboratively developing findings and interventions that will have a greater chance of being disseminated and implemented, in part due to the inclusion of decision-making and policy-making stakeholders
- Meeting the needs of public and private funders who increasingly are demanding engaged research strategies

What are the specific reasons for including community, patient, or stakeholder engagement in our research?

Consider the specific research questions or area of focus of your research and be clear about the purposes and goals of the engagement effort you are considering. How are you hoping that engagement will add to your research project’s appropriate design and focus, feasibility for success and sustainability, acceptance by a community, rigor, impact, etc.?

Key Considerations Related to Engagement before or at the Start of a Research Project

1. *What type of engagement do we need for our project?*
 - a. Engagement happens on a spectrum (<http://epa.gov/ncer/rfa/forms/cenr.pdf>). You may have more minimal engagement (e.g. outreach to inform relevant organizations about research taking place in their community) or you may have more participatory engagement (e.g. working with community/practice partner(s) to identify a mutually interesting research questions and working together to design, conduct, and disseminate the project).
 - b. Below are listed several approaches to engaged research you may hear discussed. It’s important to remember that engagement can be incorporated into any research approach (from clinical trials to genomics research), not just these.
 - Community-engaged research (CEnR) is a framework or orientation for conducting research that supports the premise that people ought to be involved in the decisions, as well as the cultivation of information those decisions are guided by, that affect their lives. It is not a methodology in and of itself. It’s characterized by the relationships between the communities and academic researchers. CEnR is used as an overarching catch phrase that captures all types of engaged research. Two examples of CEnR are described below.
 - Practice-Based Research (PBR) involves practicing clinicians/health centers, practices in asking and answering clinical and organizational questions central to health care.
 - Community-based Participatory Research (CBPR) is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities. CBPR is considered a more intensive form of CEnR.
 - c. Before you identify or reach out to potential partners, consider what type or level of engagement you’re interested in or what the project calls for. Consider your current ability to develop and maintain relationships with community partners, your project’s needs and what level of input or collaboration you want. Consider the resources and time various types of engagement will require. Consider whether you are seeking engagement only on a specific project or if you’re looking to build a long-term partnership (may span multiple projects). These may necessitate different approaches up front.

- d. Specific types and mechanisms of engagement are included below.
2. *Who are the groups or people we are trying to engage?*
- a. How do we define what we mean by patient, community, and stakeholder?
- Patients (someone with a health condition or at risk of a condition), Caregivers/Family Members of Patients_(e.g., unpaid caregivers to someone who is affected by an illness), Patient/Caregiver Advocate (e.g., those who serve in a patient advocacy role on behalf of an individual or an organization.)
 - Community may include community- and faith-based organizations, coalitions, public agencies/institutions, community members/residents. Community may also refer to organizations or individuals representing specific health issues, racial/ethnic groups, or geographic community areas.
 - Stakeholders have an interest in the research results and may include health care providers, health centers/hospitals, health insurance/payer, policy makers, other researchers, industry.
- b. Do we have existing relationships we can build on?
- c. Do we have any colleagues who can give us referrals/recommendations? If you have a mutual or connecting colleague, you may want to have them join the initial meeting.
- d. Are there any partners or coalitions focused on our issue or community of interest? **Contact CCH for assistance in identifying and connecting with CCH partners (CCH@northwestern.edu).**
3. *How should we prepare for our first connection/meeting with potential partners?*
- a. Be prepared to discuss 1) information about you, your background/experience, your current work, 2) questions you would like to ask the partners, and 3) what's in it for the partners. If you are contacting them with a specific request for engagement, also be prepared to describe the request- what you're asking of them. They may be interested in seeing a copy of the proposal and budget.
- b. Information to share: Your experience (or lack thereof) with engagement, research, topical issue, communities.
- c. Questions to ask: partner experience/capacity with research, how the partner currently supports or uses research, their research interest areas, other possible partners to connect with.
- d. What's in it for them (the potential partners)? How will their organization/practice/community benefit from the research project and findings? Prepare a brief paragraph or one page lay language summary of your interests or proposal (e.g. background/contact info for yourself, sponsor or funder of the research, how you expect the research and outcomes to affect/benefit the community).
- e. Become knowledgeable about the groups, peoples, communities you are approaching. Consider how engaging individual community members/residents/patients is different than engaging organizations or agencies or health care providers?
4. *How should we continue to establish and develop our partnership?*
- a. It is important to get to know the partners you are engaging, to establish relationships, and build trust.
- b. What mechanisms should we use to involve our partners? As discussed above, there is a range of involvement. Some partnerships include partners as Co-Principal Investigators or Co-Investigators. Some partnerships form partner advisory or steering committees. Some add partners as members to broader project committees. Some partnerships get input and feedback

- from partners throughout a project using focus group discussions, surveys, telephone discussions, forums, etc. Consider what mechanism will allow your project to get the input it needs in the project design, conduct, and dissemination. Will partners be involved in the governance of the project (e.g. how money is allocated, hiring decisions, etc.) or just on the design, conduct, and dissemination of the research?
- c. Consider developing a Memorandum of Understanding or a Letter of Agreement that provides written documentation of all partners' roles and responsibilities and decisions about relevant topics like data ownership/use, dissemination, finances, handling disagreements, etc.
 - d. What will be the communication mechanisms among partners? What individuals are the points of contact for the organization? Partner leadership or front line workers? Who needs to sign off on what decisions?
 - e. Assess the capacity of the partners and determine if additional people/expertise/organizations need to be added. Also consider if any capacity building activities or training should be conducted with partners (both community and academics).
 - f. Consider and communicate about the outcomes/impacts each partner is hoping to have with the research and why they are involved.
5. *How can we engage partners in developing research questions?*
- a. Engage partners to ensure that possible research questions or areas are relevant to partners' interests, plans, and goals. Can they use findings from this research in their work? Partners can also provide info on feasibility of answering the research question- e.g. data availability, historical efforts/relationships, and community dynamics.
 - b. You can engage partners even if research questions have already been developed. If so, it will be important to ensure the identified questions are relevant and of interest to partners. Sometimes it is possible to add research questions that have relevance to the partners.
6. *How can we engage partners in the design of our project?*
- a. Partner can advise on issues related to data collection tools/approaches, research participant incentives, recruitment ideas, logistics and other aspects of how to tailor the research and methods to the specific community or cultural context. Partners can help determine the budget necessary for their and others engagement in the conduct of the project.
 - b. Partners may have concerns about the research design if a placebo or control group is planned. They may want to ensure that no groups or individuals are 'denied a service or treatment.' Consider alternate designs that address this- e.g. staggered control groups.
 - c. Partners can identify outcome measures and predictive measures that are important or meaningful to them.
7. *How can we engage partners in proposal development? How do we describe the engaged proposal development process in our grant proposal?*
- a. Partners can provide descriptive information about the community and data from previous assessments. Partners can review proposal components or drafts. Partners can provide letters of support and consider including a description of the engagement process.
 - b. Consider administrative or contractual arrangements that may need to be made in working with external partners. Also consider whether your partner may need a FWA (Federal Wide Assurance) with an IRB.

- c. Allow time for review and feedback and incorporating changes into the proposal. Drafts need to be completed with enough lead time to allow for this.
 - d. In the grant proposal, share the ‘story’ of how you and the partners have developed a partnership and worked together to design and prepare the proposal. Share what decisions or project design choices were made based on partner input and feedback.
8. *How can we continue to support our partners while we are waiting to hear about the funding decision?*
- a. Be clear with partners from the beginning about the expected timeline and process for review and notification.
 - b. Stay in contact during the wait period as possible. Share any updates about the proposal or review as you receive it.
 - c. Consider other possible ways of collaborating during this time. E.g. help at a local health fair, provide an educational session on a relevant health issue for the community, etc.
9. *What are things our project needs to consider from the beginning?*
- a. Does our academic team (faculty, staff, fellows, students) have the resources/expertise that we need to engage communities? Do we have the skills/knowledge we need to do things like explain research concepts simply and clearly to non-experts?
 - b. Do our community/patient/stakeholder partners have the resources/expertise that they need to engage in research? Do they have skills/knowledge they need to do things like consider research design and implementation issues?
 - c. Consider doing a self-assessment/reflection of your team/partners about what skills/resources your team/partners has/doesn't have and what may need to be developed.
 - d. What are outcomes that researchers are interested in? What are the outcomes that others stakeholders are interested in? How will a project attend to both sets of outcomes?
 - e. Begin to plan for dissemination and implementation
 - f. Work on constructing a plan for data ownership
 - g. Discuss areas of possible conflict or issues that may be challenging for project
 - h. What challenges may our team face related to engagement in research? E.g. timeline may be longer, colleagues/mentors/institutional leaders may not understand engagement in research, etc.
 - i. How could programs be sustained after your study period is complete?

Key Considerations Related to Conducting an Engaged Research Project

1. *How can we engage partners in data collection efforts?*
- a. Partners can provide input on research methods that will be well-received by a community. Should quantitative, qualitative, or mixed-methods approaches be used?
 - b. Partners can provide input on data collection protocols that can facilitate successful acquisition of data.
 - c. Partners can provide input on measures/instruments that will be feasible and acceptable to communities. There may need to be a balance between using psychometrically valid measures and incorporating measures or questions that are community-generated or patient-centered.

- d. If appropriate, partners can be hired or identify appropriate candidates to be hired as part of the research team to collect data or implement interventions.
2. *How can we engage partners in recruitment and retention of study participants?*
 - a. Partners can provide input on recruitment materials, which can enhance how well communities understand the study being described.
 - b. Partners can provide input on optimal sites for recruitment, which can enhance accrual of study participants.
 - c. Partners can provide insights on strategies for retaining study participants, including selecting appropriate incentives and determining appropriate time/location of intervention and data collection procedures.
 - d. Partners can help to promote the study to appropriate possible participants.
 3. *How can we engage partners in data analysis?*
 - a. Partners can provide input on the interpretation of process and outcome data emerging from a study. Do community partners have the same interpretation as researchers? If not, why not?
 - b. Partners can provide input on how to translate study findings into meaningful and easily understandable formats that are accessible to community members who were study participants.
 4. *How can we maintain strong partnerships during the implementation of a research project?*
 - a. Consider the different ways in which partners like to receive information and engage partners in those formats (e.g., email, phone, text message).
 - b. Establish clear expectations for the roles and responsibilities that partners will play. This includes being clear on what type of input partners will be asked to provide and what type of time commitment is involved (e.g., attending advisory meetings, reviewing documents).
 - c. Provide ongoing and clear communication about study activities, timelines, milestones, requests from funding agencies, etc.
 - d. Consider conducting periodic evaluation of the partnership process as a quality improvement tool.
 5. *How do we handle dynamics among different community stakeholders who are working with us?*
 - a. Develop norms and procedures for getting input from stakeholders that allow all stakeholders to contribute to discussions and decision-making, not just the “dominant” voices.
 - b. Attempt to understand stakeholders’ previous working relationships to anticipate potential disagreements and tensions among partners
 6. *How do we build in benefits for community stakeholders who are working with us?*
 - a. Are there ways to provide services (e.g., workshops, educational materials) to partners either related or unrelated to the project that is being conducted?
 - b. Is there a way that community economic development can be considered? For example, is it appropriate to hire/train community members as part of the research team? Is it possible to use community vendors/local businesses for any supplies, services, or food that needs to be purchased?
 - c. Continue to have discussions about how project findings will be used by community partners to influence policy and practice at the organization, local, state, etc. levels.

- d. Provide capacity building on research design, methods, phases, etc.
7. *How do we think about the sustainability of programs created through the partnership?*
- a. Consider sustainability early in your planning so you can insure that the program design could be maintained and that you are collecting the evaluative data necessary to determine the merit of its continuation.
 - b. Discuss with your partners how to sustain a program or practice change after your initial funding is over.
 - c. What value could the program provide to their organization?
 - d. Recognize that programs or practice improvements involving procedural changes may be easier to sustain than programs requiring additional manpower.

Key Considerations Related to Dissemination of Engaged Research

1. Discuss preliminary dissemination plans with your community partners. What kind of information do they need to obtain from the project? What value does the study provide to their organization? Have these conversations as early as the start of the project so you can insure that you are collecting the data necessary to address the community needs for information.
 - a. Discuss both community and academic dissemination plans, including possible article publication (insure data elements are being collected), presentations, authorship, and plans for collaborative writing and presentation.
 - b. Identify stakeholders who may be interested in study results. Are you collecting appropriate data to answer questions of interest for each audience? Consider:
 - Patients/caregivers, Public/community, Healthcare Providers/Service Providers, Purchasers, Payers, Policy makers/public agencies, Product makers, Other researchers
2. *Once you have the study results, consider the following.*
 - a. Decide what findings or messages from the study deserve to be shared
 - Discuss what each partner feels are key findings, why they feel they are important and the strength of evidence
 - Disseminate your process too- share your lessons learned about partnerships, not just research findings
 - b. Consider what audiences would benefit from the information
 - Review your list of stakeholder groups with partners. Are there additional stakeholders? Consider who has the power to make changes indicated by the findings? How can these decision makers be engaged?
3. *Consider dissemination venues or mechanisms relevant for your stakeholder groups*
 - Study participants: individualized letter with results or more general lay summary of research findings, study newsletter during and after the project
 - Patients/public/community: Community/Organizational newsletter articles, Social Media/Listservs/Website/ YouTube, News Media (print, radio, TV- coverage, purchased, community/ethnic media). Consider engaging university PR/Media contacts. Hold Community events- town hall, workshops, advocacy, faith sermons/ settings. One-one communication, word of mouth. Maps/Photovoice/Art/Theater. Community Fact Sheets, posters, flyers www.CES4health.info. Handbooks/toolkits.

- Healthcare and Service Providers: coalitions/local medical societies, newsletters, presentations at coalition/professional society meetings, maps, www.CES4health.info Handbooks/toolkits, curriculum.
 - Purchasers/Payers: policy briefs
 - Policy makers: Policy Brief/White paper, lobbying, testimony- ID key policymakers www.CES4health.info, invitation to community events. Connect with Northwestern Government Relations office about appropriate connections.
 - Product makers
 - Other researchers: publications, presentations
 - Funders: study report
4. *When crafting dissemination, what are some key considerations?*
- a. Consider language/literacy needs and use of photos and graphics.
 - b. Consider language translation needs
 - c. Who makes presentations? Involve community partners in academic dissemination and academic partners in community dissemination. Speak together, present at conferences together.
 - d. Dissemination is about exchange, feedback. It's not information going one way.
 - e. Partners can help to frame outcomes that communities feel are 'bad news' in a way that won't damage the community or cause further disenfranchisement.

Key Considerations Related to an Engaged Research Project as it Nears Completion

1. *What are the next steps?*
 - a. Are there findings that merit dissemination or further implementation?
 - b. How can we translate findings into new settings (scaling up)?
 - c. What types of settings might benefit from your study's findings?
 - d. What research questions have emerged from your study's findings?
 - e. Consider other data collection efforts
 - Additional data collection or other sites?
 - Consider whether your research findings might inform an intervention or practice change
2. *Address financial/staffing changes*
 - a. Anticipate project staff that may no longer be supported with grant funding
 - b. How to sustain a program/service/intervention without grant funding?
3. *Consider whether the relationships should continue after the project ends*
 - a. Continue contact as feasible, possibly sharing relevant findings from other studies
 - b. Consider the implications of moving forward without funding
 - c. Consider whether new partners are needed as the research or implementation focus evolves