Community and Stakeholder Engagement in Health Research:
Guidelines Offered by NC TraCS

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Introduction

The [Community and Stakeholder Engagement Program at NC TraCS](#) works to promote and facilitate the development of long-lasting and meaningful research partnerships between clinical and translational researchers and diverse stakeholders from across North Carolina. When implemented with planning and open-mindedness, community and stakeholder engagement in health research has the potential to generate research and research findings that are highly relevant for the populations uniquely affected by the targeted health conditions of research studies. The creation of equitable community and stakeholder partnerships can better inform some of the *What, Why, Who, How, When and Where* of clinical and translational health research.

Within this document, we provide guidelines and suggestions for the appropriate and effective engagement of stakeholders in health research. Specifically, we outline the importance of community and stakeholder engagement in research, suggest engagement approaches and guidelines for researchers, offer examples of engagement activities, and outline strategies for recognition and compensation of research stakeholders.

We are happy to work with you in developing your community and stakeholder engagement activities, from planning to implementation! Please contact us for a consultation at engagement.nctracs@unc.edu, or submit a request online at https://tracs.unc.edu/consultation.

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Importance of community and stakeholder engagement

Community and stakeholder engagement is defined as *"the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices."* [1]

In regards to health research, this definition highlights the immense value stakeholders - or those people or organizations invested in a research area or project and/or impacted by its effect, success, or failure- can bring to a research team's agenda. When engaged in a meaningful way, stakeholders can help to ensure the relevance and sustainability of health research in their communities, and can guide study teams on how best to generate community support and trust in their research.

When to engage stakeholders in your research

It is never too early to involve stakeholders in your research! Stakeholders can provide valuable input at all stages of a research study – from conceptualization, to design, to implementation, to dissemination. Stakeholders may offer insight that can help guide your research in a way you did not anticipate, so early engagement is recommended.

Some key questions to consider at the outset of a research study include:

- **What** are you proposing to study?

- **Who** will your research benefit? Who has the insights that can inform your research? Who will you hire as your research staff? Who will be your gatekeepers, stakeholders, allies, and funders?

- **When and where** will your study take place?

- **Why** is your study relevant to the health and well-being of communities/ populations you will be recruiting to participate?

- **How** will you implement your research design? How will you disseminate study results?

It is important to consult stakeholders regarding these questions to ensure an approach that is relevant and feasible. Through consulting with stakeholders, researchers' answers to the above questions may shift. ***The purpose of stakeholder engagement is change.*** If your plans alter through the process of engagement, it's working. If you are finding blanket approvals of your work-to-date without suggestions for improvement, you may want to reconsider your engagement goals and strategies.

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[1] *CTSA Community Engagement Key Function Committee. "Principles of community engagement." (2011): 11-7782.*

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The level of stakeholder engagement necessary over the course of a study's lifecycle can vary according to the unique needs of stakeholders and researchers. *One size does not fit all.* Depending on the level of engagement that a community-academic partnership seeks, teams will need to determine when and how to involve stakeholders over the life course of a study. **Some examples of ways that stakeholders can contribute to and be involved in projects throughout the research lifecycle include:**

- Helping to generate your research question and strategies;
- Reviewing and meaningfully contributing to your grant proposal prior to submission to ensure its feasibility and relevance for its target population;
- Serving as a member of your research team to carry out project tasks over the lifecycle of a project;
- Developing and disseminating user-friendly study materials (e.g., recruitment materials, questionnaires, medication guidelines, diaries, etc.); and
- Disseminating study results back to their constituent communities

It is also important to ensure that engagement strategies account for the strengths, expertise, and availability of stakeholders, particularly if these partners do not have formal research training. Research teams should be cognizant that some stakeholders may require time to become acquainted with academic culture, research expectations, and institutional bureaucracy.

We recommend financial compensation for stakeholder involvement at all stages of research [*see the "Financial and logistical considerations for stakeholder engagement" section below for further details regarding compensation*]. At the outset of the partnership, research teams and stakeholders should clarify expectations regarding the level and length of involvement, as well as the compensation to be provided. Research teams should consider drafting Memorandums of Understanding that clearly outline the roles and responsibilities of both stakeholders and researchers. These steps are crucial in generating trust in the partnership. It is also recommended that a Letter of Support be obtained from key stakeholder partners as part of the grant application process, and that this letter clearly stipulate roles, responsibilities, and expectations for the partnership. These stipulations should be reflected in the grant proposal's budget and budget justification.

How to engage stakeholders in your research

The Community and Stakeholder Engagement Program at NC TraCS can help you create an engagement approach most suitable for your study and the needs of your research team and stakeholders. While stakeholder engagement can take many forms, authentic stakeholder engagement approaches should consider the following criteria:

- The project/grant outcomes include outcomes that are important to stakeholders.

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- Stakeholders are involved in the design, planning, implementation, and/or governance of the study, and/or dissemination of results
- Study results/findings are shared with the communities/populations they impact in usable ways
- The research protocol does not put unnecessary burden on research participants

Stakeholder engagement activities vary in their level of involvement and commitment required. Some examples of stakeholder engagement activities are listed below, ranging from low to high involvement levels:

- Seeking suggestions from stakeholders periodically via surveys or individual conversations
- Seeking feedback via occasional group events, such as listening circles
- Forming advisory boards of stakeholders that meet regularly and have an internal structure in which the researcher can serve as a facilitator or listening member
- Creating avenues in which stakeholders have decision-making roles in the research process (e.g. having a key stakeholder serve as co-Investigator).

Levels of involvement may change and grow over time. Engagement activities at lower ends of the involvement spectrum may pave the way for greater levels of stakeholder involvement in the future. The table below provides an overview of the varying levels of involvement, and what each may entail. You can also read more about the levels of involvement and characteristics of these activities in chapter 1 of *Principles of Community Engagement.*

	Inform	Consult	Involve	Collaborate	Delegate	Community Driven/ -led
Community Participation Goal	To provide the community with balanced & objective information to assist them in understanding the problem, alternatives, opportunities &/or solutions	To obtain community feedback on analysis, alternatives, and/or solutions	To work directly with community throughout the process to ensure their concerns and aspirations are consistently understood and considered	To partner with the community in each aspect of the decision including the development of alternatives & identification of the preferred solution	To place the decision-making in the hands of the community	To support the actions of community initiated, driven and/or led processes
Promise to the community	We will keep you informed	We will keep you informed, listen to & acknowledge concerns, aspirations, & provide feedback on how community input influenced decisions	We will work with you to ensure that your concerns & aspirations are directly reflected in the alternatives developed and provide feedback on how that input influenced decisions	We will look to you for advice & innovation in formulating solutions and incorporate your advice & recommendations into the decisions to the maximum extent possible	We will implement what you decide, or follow your lead generally on the way forward	We will provide the needed support to see your ideas succeed
Examples	•Fact sheets •Web sites •Open Houses	•Public comments •Focus groups •Surveys •Community meetings	•Workshops •Deliberative polling •Advisory bodies	Advisory groups •Consensus building Participatory decision making	Advisor bodies •Volunteer/ stipend •Ballots •Delegated decision	•Community supported processes •Advisory bodies •Stipend roles for community •Funding for community

Best practices for engaging stakeholders

For additional information about stakeholder engagement during the COVID-19 pandemic, including strategies for virtual engagement, please download our [Tips & Tools for Stakeholder Engagement during COVID-19](#) guidance document at http://go.unc.edu/engagement-during-covid-19.

When creating an engagement plan for your study, research teams should carefully consider their approach. Key considerations for engaging stakeholders are listed below.

- **Strategically consider** who you want to invite to be stakeholders and ask them for guidance in finding others who may want to be involved. Ask stakeholders what would make partnering with your research beneficial to them.
- **Create a welcome packet** for stakeholders to help orient them to the experiences they will have during the term of engagement. Include activity schedules, your contact information, and a brief description of the research. Sometimes more formal documents like a Memorandum of Understanding or Bylaws are useful if the level of engagement and commitment will be high. [The Community and Stakeholder Engagement Program at NC TraCS](#) can provide your study team with examples of such resources, and can review and provide input on documents created by your team.
- **Provide capacity-building** opportunities for stakeholders throughout their involvement. Through this partnership they should gain knowledge about health research and the area of health the study addresses. Offer training or mentoring in areas in which stakeholders will be involved, such as grant writing or data analysis.
- **Clarify** your expectations for stakeholder input. Are you seeking stakeholders who will share their individual experiences with health issues and the health care system? Are you seeking stakeholders who will speak on behalf of groups with which they identify?
- **Consider group dynamics** if you will have stakeholder meetings. Groups with less than five members may not have enough interpersonal energy to generate discussion. Groups with more than 10 members can become unwieldy and you may only hear from the more outgoing members. Make sure that everyone can see someone else like them in the group. For example, if there is only one stakeholder in a group who is older than 60 and others are younger than 40, this person may feel like a token elder or an outlier in discussions.
- **Budget** for stakeholder compensation throughout the project. Create the line item for stakeholder compensation in each fiscal year of the grant.
- **Food** always helps groups to come together. Talk to your grants manager and find ways to incorporate food as a line item in your budget.
- **Create a welcoming environment** for your meetings and **consistently express gratitude** in your communications with stakeholders.
- **Celebrate successes** along the way. Let stakeholders know when project goals are met and thank them for their contributions.
- **Mark transitions** with stakeholders. If the study is ending, host an event to inform stakeholders and their communities of the work accomplished. Recognizing

stakeholder contributions with certificates, photos, or other items that represent the study is one way to close the shared time together and honor their contributions.

- **Evaluate the success of your engagement.** Periodically deliver brief surveys to your stakeholders to assess their satisfaction with your partnerships. Use the information gathered to improve your engagement strategies and strengthen your collaborations. The Community and Stakeholder Engagement Program at NC TraCS can provide your study team with sample questions and can review and provide input on questions drafted by your team.
- **Recognize, honor, and thank** everyone who joins you in this work.
- **Maintain your relationships with stakeholders.** Don't disappear after the study ends. Maintaining communication with your stakeholder partners and a presence in the communities involved in your research builds trust and paves the way for future engagement opportunities.

Strategies for stakeholder recognition as university partners

Utilizing the prestige of the university to recognize stakeholder efforts contributes to building an ongoing relationship with communities. Oftentimes effective strategies of stakeholder recognition complement financial compensation to build lasting community – academic partnerships that would not survive on either strategy alone. We encourage research teams to be creative in the ways in which they recognize and support their stakeholder partners. Below are just some of the many strategies research partnerships should consider.

- Provide leadership or training opportunities for stakeholders that will enrich their personal resumes and CVs.
- Offer your expertise as an academic to communities. Ask stakeholders if there are ways in which you, or your research team, can help to address their, or their organization's, capacity-building needs.
- Invite stakeholders to co-author publications with your team.
- Invite stakeholders to present with you at conferences and fund their participation.
- Show up for stakeholders as you ask them to show up for you. Showing up can mean joining an advisory board for a nonprofit agency, speaking at community events when invited, and volunteering in communities in any capacity that stakeholders open to you.

Financial and logistical considerations for stakeholder engagement

Your research budget must support both the compensation of stakeholders, as well as the logistics of engaging stakeholders. Several key budget and logistical considerations are outlined below.

Stakeholder Compensation:

Stakeholders should be compensated for the time and expertise they dedicate to your study. This could include time spent in meetings, on review panels, and conducting study

activities. We recommend compensating stakeholders at a market rate (approximately $50 per hour in 2019) and coming to an agreement beforehand as to how many hours will be required.

In order to be paid by UNC, stakeholders must be established as vendors in the UNC payment system. There are two main types of vendor relationships – **organizations** and **individuals**. For additional information about becoming an organizational vendor or individual Independent Contractor at UNC, visit https://finance.unc.edu/services/becoming-a-vendor-with-unc/, speak with your department's Business Office, or contact the Community and Stakeholder Engagement Program at NC TraCS.

- **Organizations, agencies, and multiple owner LLCs** can be compensated as vendors. Organizations must be approved by UNC as vendors *before* work begins.

- **Individuals** are considered Independent Contractors. They must be approved by UNC as Independent Contractors *before* work begins. They must complete a form for each department and project that they work on each year to maintain Independent Contractor status. Independent Contractor status is renewed each fiscal year (July 1 – June 30). Individuals who are employed by a North Carolina state agency *cannot* be compensated as Independent Contractors. Additional information about becoming an Independent Contractor at UNC is available at https://unc.policystat.com/policy/4756349/latest/.

Stakeholders who are not Independent Contractors can be reimbursed for certain expenses, such as travel expenses, by completing and submitting the OPIC form (available here: https://unc.policystat.com/policy/5379145/latest/) and a W-9 form.

It is important to note that compensating a **research participant** is a different process than paying a **research stakeholder**. Please consult your department's Business Office or the Community and Stakeholder Engagement Program at NC TraCS for additional information and guidance regarding compensation and payment mechanisms.

Meeting Expenses and Logistics:

Please note: the majority of the meeting expenses and logistical considerations discussed below refer to in-person meetings. For additional information about virtual stakeholder engagement practices, which are increasingly important during the COVID-19 pandemic, please download our Tips & Tools for Stakeholder Engagement during COVID-19 guidance document at http://go.unc.edu/engagement-during-covid-19.

If you are planning to host meetings for your stakeholders (which we recommend doing on a regular basis), be sure to plan for feasibility and budget for related expenses. Speak with your department's Business Office in advance to determine how these meeting expenses should be paid (e.g., via p-card vs. as a vendor or Independent Contractor). Such expenses for in-person meetings include venue rental, food, childcare, language interpreter services, and travel costs.

Venue:

Meeting locations should be convenient for stakeholder partners. Consider choosing locations near your stakeholders (rather than near the university), with easy access to public transportation and ample parking.

Food:

We recommend providing healthy food at in-person meetings, including beverages, meals for meetings at mealtimes, and snacks for meetings at other times. Be cognizant of dietary preferences/restrictions (e.g., gluten-free, vegetarian/vegan, allergies) and have options available to accommodate all meeting attendees.

Childcare:

To facilitate the inclusion of parents with young children as stakeholders, we encourage researchers to contract with professional childcare providers who are CPR certified and who have provided references for their experience in early childhood education and care. Parents attending can be asked to sign a form indicating that they understand that they are ultimately responsible for their child's well-being during the meeting.

- We recommend that childcare professionals be compensated for an hour of set-up time for environments that are not designed for children as well as for an hour of clean up afterwards.
- Although North Carolina child care regulations may allow for higher ratios of children per early childhood professional, we recommend that child care providers be provided in the lower ratios approved by the National Association for the Education of Young Children (NAEYC). A minimum of 2 child care providers per event is recommended. https://dphhs.mt.gov/Portals/85/hcsd/documents/ChildCare/STARS/Kits/3to4centerteachertochildratiochart.pdf

- Allowing parents of infants and toddlers to keep their infants with them during meetings can also facilitate the participation of parents of young children. Encourage mothers who breastfeed to feel free to do so during meetings. Having only female research staff for these meetings can also support the participation of breastfeeding mothers.
- If the research team chooses to have child care provided by volunteers, these volunteers and the children *must stay in the room with the parents*. CPR certification is strongly recommended for volunteers.

Travel:

Consider providing validation for parking, bus passes, or reimbursement for any mileage a stakeholder might incur. Cover these costs in addition to the compensation

and ahead of time, so that stakeholders will be able to receive the full compensation payment and do not have to pay out of pocket.

Language Interpretation:

If working with populations whose primary language is other than English, budget for a certified interpreter to be present at study meetings. The use of certified translators is also recommended when developing study materials in another language.

Resources for developing an appropriate stakeholder engagement strategy

We recommend that you consult with the staff and faculty of the Community and Stakeholder Engagement Program at NC TraCS. They can provide expertise and guidance related to community and stakeholder engagement approaches and best practices suited for your research. Please contact us for a consultation at engagement.nctracs@unc.edu, or submit a request online at https://tracs.unc.edu/consultation.

There are also several online resources that can help supplement this guidance. Check out our website for some select resources: https://tracs.unc.edu/engagement/training. Additional resources are listed below.

General Community Engagement Resources:

- Principles of Community Engagement (2011): https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf
- Sample Engagement Plans from PCORI Funded Projects (2015): https://www.pcori.org/sites/default/files/PCORI-Sample-Engagement-Plans.pdf
- The Community Toolbox: https://ctb.ku.edu/en
- Tips and Tools for Community Engagement during COVID-19: http://go.unc.edu/engagement-during-covid-19

Community Advisory Boards:

- Toolkit for Developing a Community Advisory Board for Research, Southern California Clinical and Translational Science Institute: https://sc-ctsi.org/resources/developing-a-community-advisory-board-for-research-toolkit
- Newman SD, Andrews JO, Magwood GS, Jenkins C, Cox MJ, Williamson DC. Community advisory boards in community-based participatory research: a synthesis of best processes. Prev Chronic Dis 2011;8(3): http://www.cdc.gov/pcd/issues/2011/may/10_0045.htm.
- Development, Implementation, and Evaluation of a Community Engagement Advisory Board (Webinar). Matthews P (2018): https://trialinnovationnetwork.org/2018/02/21/development-implementation-and-evaluation-of-a-community-engagement-advisory-board/

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Partnership Building:

- Toolkit for Developing Community Partnerships, Southern California Clinical and Translational Science Institute: https://sc-ctsi.org/resources/developing-community-partnerships-toolkit
- Charrettes: A Charrette is a facilitated consultation session for community-academic partnerships interested in strengthening their research approach, engaging new stakeholders, or building their research partnership. The Community and Stakeholder Engagement Program at NC TraCS hosts the Charrette program. To learn more, visit: tracs.unc.edu/engagement/charrettes
- Asset Mapping: A process that allows for the recognition and acknowledgement of the strengths and assets that each partner brings. https://healthpolicy.ucla.edu/programs/health-data/trainings/Documents/tw_cba20.pdf
- Full Value Contract: Document that outlines the value of every partner and lists the values that guide the partnership. Partners can sign this document in recognition. https://training-wheels.com/full-value-contract/

Financial considerations:

- NC TraCS Fiscal Readiness Guides for Researchers & Community Partners (2015): https://tracs.unc.edu/index.php/services/engagement/community-academic-grants
- PCORI Guidelines for Budgeting for Engagement Activities (2016): https://www.pcori.org/sites/default/files/PCORI-Budgeting-for-Engagement-Activities.pdf

Interpretation and Translation:

- The National Council on Interpreting in Health Care (NCIHC) guidance on the provision of language access services for health care professionals (also useful for health researchers): http://www.ncihc.org/faqs-for-healthcare-professionals
- The American Translators Association's guides on selecting and hiring professional translators and interpreters: https://www.atanet.org/publications/getting_it_right.php
- The UNC Office of Human Research Ethics' list of resources for locating local professional translators and interpreters: https://research.unc.edu/human-research-ethics/resources/ccm3_019066/

Shared Decision Making:

- De Bono's Six Thinking Hats: A technique for looking at decision making from different points of view. It allows emotion and skepticism to be brought into what might normally be a purely rational process, and it opens up the opportunity for creativity within decision-making. https://www.mindtools.com/pages/article/newTED_07.htm
- Concept Mapping:
  - https://www.sciencedirect.com/science/article/pii/0149718989900165
  - https://www.publichealth.pitt.edu/behavioral-and-community-health-sciences/research-practice/bchs-centers-institutes/concept-mapping-institute