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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>.

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*

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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 program 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.

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.

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

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Some examples of ways that stakeholders can contribute to and be involved in research 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

We recommend financial compensation for stakeholder involvement at all stages of the research lifecycle [see the *“Financial 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.

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 includes outcomes that are important to stakeholders.
- 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 interviews;
- Seeking feedback on study materials and outreach strategies in occasional group events such as listening circles;
- Forming advisory boards of stakeholders that meet regularly and have an internal structure of which the researcher can serve as a facilitator or listening member; and

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- Creating avenues in which stakeholders have decision-making roles in the research design formation, staffing, and community presence. If stakeholders are part of a community agency, subcontracts can give back to communities some stabilizing support for their efforts.

Levels of involvement may change and can grow over time. Stakeholder engagement activities at lower ends of the involvement spectrum may pave the way for greater levels of stakeholder involvement in the future. You can read more about the levels of involvement and characteristics of these activities in chapter 1 of [Principles of Community Engagement](#).

Best practices for engaging stakeholders

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.
- **Creating a welcome packet** for stakeholders can 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 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** activities 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 other 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 health issues and histories with 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 5 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.

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- **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 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 the building of an ongoing shared 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 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 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 2018) 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 – **companies** (including not-for-profit companies) and **individuals**.

- **Companies** may be set up as a vendor by supplying a completed IRS form W-9. Note that Single-owner LLCs must follow the Independent Contractor process like individuals.
 - Organizations, agencies, and multiple owner LLCs wishing to serve as research stakeholders may apply for university vendor status through the NC TraCS Research Ready Stakeholder Program. For more information, visit: <https://go.unc.edu/stakeholder>
- **Individuals** are considered Independent Contractors. They must complete a form for each department and project that they work on each year to maintain Independent Contractor status. An Independent Contractor status is renewed each fiscal year (July 1 – June 30) and is therefore an appropriate option for an individual who may be involved in multiple projects or contracts over the course of a year. A completed IRS form W-9 must also be submitted. For individuals working with protected populations, a background check may be required. For more information, visit: <https://financepolicy.unc.edu/policy-procedure/708-independent-contractor>

Sometimes there is not funding available to compensate stakeholders for their time spent working on a project. However, there may be funding to pay travel expenses according to State guidelines, for example, automobile mileage. In this case, an individual does not have to be set up as an independent contractor and the department may pay travel using a simple form (available here: https://financepolicy.unc.edu/files/2014/12/1218_1_1f-Outside-Party-Individual-Certification.pdf) and a completed W-9.

It is important to note that compensating a **research participant** is a different process than paying a **research stakeholder**. We encourage research managers to 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.

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Meeting Expenses:

If you are planning to host meetings for your stakeholders (which we recommend doing on a regular basis), be sure to budget for related expenses. Such expenses include:

Venue rental:

- Organizations renting facilities to researchers will need to provide a tax identification number for the payment.
- With a written rental agreement, researchers may pay for the rental and then file for reimbursement.
- The renting organization can submit an invoice to the department administering the award, including the rental rate. The department will then generate a check for the organization.

Provision of food:

- Researchers may no longer use university credit cards, known as “P cards”, to purchase food for meetings. Rather, investigators must purchase the food for meetings and turn in receipts for reimbursement.
- When submitting receipts for reimbursements for food purchases, UNC requires that an agenda of the meeting and a list of those who attended be included. Only food for non-UNC staff employees is reimbursable.

Child Care:

To facilitate the inclusion of parents with young children as stakeholders, we encourage researchers to contract with professional child care 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.

- Child Care professionals can be compensated as Independent Contractors, or hired as part-time temporary employees if there will be an ongoing need for their services.
- We recommend that child care 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/3to4centertea_chertochildratiochart.pdf

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- 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 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. These 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
- SC CTSI: Toolkit for Developing Community Partnerships:
<https://sc-ctsi.org/resources/developing-community-partnerships-toolkit>
- Sample Engagement Plans from PCORI Funded Projects (2015):
<https://www.pcori.org/sites/default/files/PCORI-Sample-Engagement-Plans.pdf>

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Community Advisory Boards:

- SC CTSI: Toolkit for developing a Community Advisory Board for Research: <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.
- Matthews P (2018). Webinar: Development, Implementation, and Evaluation of a Community Engagement Advisory Board: <https://trialinnovationnetwork.org/wp-content/uploads/2018/02/2018-02-21-11.00-Development-Implementation-and-Evaluation-of-a-Community-Engagement-Advisory-Board.mp4>

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 http://research.unc.edu/offices/human-research-ethics/resources/ccm3_019066/