Guiding Principles for Community-Engaged Research

Preamble: The University of Minnesota's Clinical and Translational Science Institute and its Community partners are continuing on a path to seek new knowledge in ways that will lead to better outcomes and sustainable change in the area of health. Some drivers of the need for this collaboration are the desire to generate ideas together, reduce the time lag between research and implementation, and, truly partner with each other in order to improve the health of Minnesotans. The following overarching principles outline how we will cooperate with each other and are intended to complement existing guidance statements that have been created by the University of Minnesota and other organizations. Links to additional resources and reference are included in this document to assist University researchers and Community partners in planning and implementing research partnerships.

Guiding Principles

1. Understand that the concept of "community" is fluid. Additionally, know that the University of Minnesota is a complex institution with fluid boundaries.

There are many different definitions of "community." For the purposes of engaged or partnership research, it is important for partners involved in a project to come to an understanding about the "community" to be defined. Questions to consider in the process of defining the community include[i]:

- Are those most affected by the problem at the table?
- Are those who have a stake in the issue being addressed at the table?
- Do they play decision making roles?

2. Mutual identification of the wants and opportunities expressed by the Community and the University researchers

The University and Community will leverage each others' strengths and come together on issues that are deemed important and that can be impacted by new knowledge that is (can only be) created in partnership.

3. Genuine involvement of University researchers and Community in the development of projects

We will be truly engaged in the co-production of new knowledge that can be turned into actionable results. The collaboration will be demonstrable and transparent, reflecting trust and authenticity.

4. Research data will be collected, analyzed and shared appropriately between partners and they will come together in a way that is respectful and recognizes the value of the data collected

The essence of this principle lies in honesty, transparency of data and the spirit of true partnership. We must honor the privacy and confidential use of information that is collected and becomes research data. We will support one another in the protection of the rights, privacy and safety of those who choose to participate in research. We will use the data to answer research questions, while balancing the needs to generate new research questions with safeguards against misuse of the data by either partner.

5. Research results will be interpreted in partnership and turned into actionable steps through community-guided dissemination and implementation strategies for the improvement of community and individual health

Research and new knowledge that is co-produced will be carefully interpreted to ensure fruitful implementation of learning and sustainability spread to other areas within the community. We will focus on research with the goal to expedite the time between generation and its impact on individuals, their families, and community health.

Background

The Clinical and Translational Science Awards (CTSA) Program was implemented by the National Institutes of Health (NIH) to meet the challenge of creating more direct and faster connection between clinical research and improvements in the public's health. The National Center for Advancing Translational Sciences has been charged by the NIH with supporting institutions nationwide that are committed to restructuring their research infrastructure through the CTSA program. A CTSA award signals an institutional commitment to including communities in the research process and in the translational of research findings into "real world" applications.

Figure 1: Guiding principles of the CTSA program

Truly changing the research infrastructure can only be accomplished by: 1) **engaging communities as valued members of the research team,** and 2) **by building stable infrastructure within communities not only to ensure their capacity to participate in research but also to implement new knowledge in ways that will lead to better health outcomes and sustainable community change.**[ii] With community engagement as a key component of every CTSA, researchers engage in collaborations with stakeholders to advance translation. Communities and universities are seeking new ways of working together to inform the research process and translate research findings into practical applications with an ultimate goal of improving the public's health.

In 2009 the University of Minnesota leadership created the Clinical and Translational Science Institute (CTSI) to more broadly engage community in the research process and the translation of scientific breakthroughs into real world applications. CTSI's Office of Community Engagement to Advance Research and Community Health (CEARCH) creates opportunities for the public to contribute meaningfully to translational research and for community and university research teams to collaboratively develop, implement, and disseminate research and knowledge. CEARCH seeks to provide community members and university researchers with the infrastructure, tools, resources and support to co-produce knowledge that will lead to improvements in health for all. These principles serve as a guide for communities and researchers to use at any point in their collaboration process.
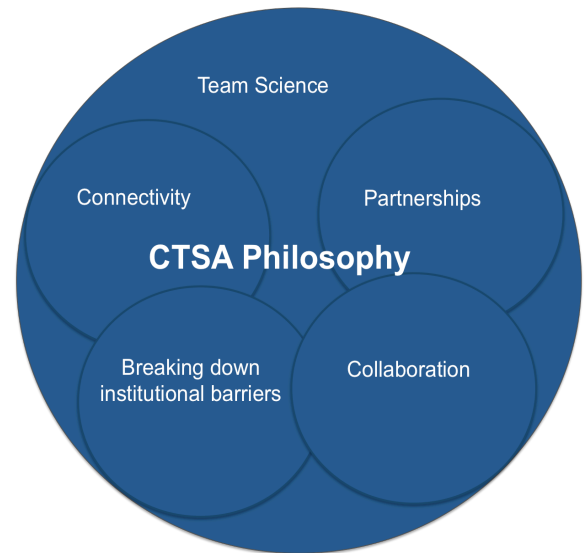
Definitions

University Researchers:[1] University researchers are defined as students, faculty, post-doctoral fellows, or staff housed at an institution of higher education.

Community: There are many different definitions of "community." Community can be defined as: "A group of people with a shared social structure and modes of interaction based on collective norms and values."[iii] Alternatively, membership in a community can be by choice or based on some innate trait such as race, ethnicity, sexual orientation, and gender identity. Community can be defined by organizational affiliation or geographic boundary. Membership in a community can be fixed or fluid.[i]

The University of Minnesota's CTSI defines community broadly and seeks to engage a diverse group of stakeholders in research such as:

- Special populations of diverse race, ethnicity, country of origin, socioeconomic status, age group, gender, and geographic location
- Civic, community-based, and faith-based organizations
- Public sector agencies engaged in health promotion and disease prevention
- Healthcare organizations and professionals
- Policy makers
- The general public

Clinical research: Clinical research can be defined as scientific studies that involve people to test the safety and efficacy of new disease prevention strategies, diagnostic tools, drugs, and treatments. Clinical research can be conducted in a university academic health center setting or can involve individual or multiple community settings. All clinical research is guided by a set of quality, ethical and safety standards.

Translational research: Translational research is the movement of scientific discoveries from "bench-to-bedside" – that is the *translation* of basic science discoveries made in laboratory settings into "real-world" application in the clinical setting and further application into population health. The translation of knowledge occurs both *from* the researcher *to* the clinician and *from* the clinician *to* the researcher in order to advance scientific discoveries. Translational research can be further defined to encompass the movement of knowledge between researchers and community-based practitioners beyond the clinical setting.

Community-based or Community-engaged research refers to research that takes place in or involves a community, with the degree of community engagement in the research typically occurring along a continuum.[iv] Community engagement in research can range from 'academically driven' projects involving a one-time, short-term relationship with an academic researcher who defined the research project to 'community driven' research projects, such as community-based participatory research, which are co-defined by an academic researcher and community partner with equal sharing of power and decision-making to ensure benefit to both parties.[iv,v]
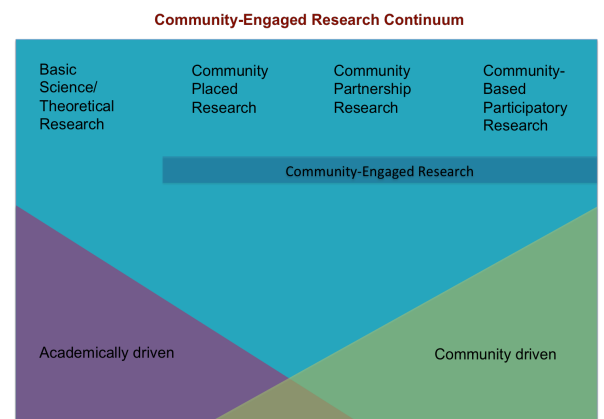
Figure 2: Community-engaged research continuum

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[1] *We recognize that researchers are not exclusively within the university setting and that many community organizations possess the capacity to conduct research projects outside the university. For the purposes of this document we are specifically referring to researchers who are affiliated with an academic institution. However, these principles can apply to all who identify themselves as researchers.*

Office of Community Engagement to Advance Research and Community Health | CTSI

Resources

Clinical and Translational Science Awards websites, ctsacentral.org and ncats.nih.gov/community

Clinical and Translational Science Institute at the University of Minnesota, ctsi.umn.edu

Community-Campus Partnerships for Health, ccph.info

Community-Campus Partnerships for Health Board of Directors. Position Statement on Authentic Partnerships. 2013, ccph.memberclicks.net/principles-of-partnership

Gust S. and Jordan C. The Community Impact Statement: A tool for creating healthy partnerships. Minneapolis, 2006.

Institute of Medicine. The CTSA Program at NIH: Opportunities for Advancing Clinical and Translational Research. Washington, DC: The National Academies Press, 2013, ncbi.nlm.nih.gov/books/NBK144067

University of Minnesota Office for Public Engagement, engagement.umn.edu

References

[i] Community-Campus Partnerships for Health Board of Directors, 2005, ccph.memberclicks.net/faq

[ii] The Clinical and Translational Science Award Consortium's Community Engagement Key Function Committee, CTSA Community Engagement Workshop Planning Committee. Researchers and Their Communities: The Challenge of Meaningful Community Engagement. Bethesda, MD: National Center for Research Resources; 2009.

[iii] Centers for Disease Control and Prevention and the Agency for Toxic Substances and Disease Registry (2011). Principles of Community Engagement, 2nd Edition. NIH Publication No. 11-7782. Washington, DC, http://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

[iv] University of Minnesota. 2009. Performance of Community-based Research: Guidance Statement.

[v] Israel, BA, Schults, AJ, Parker, EA, Becker, AB. Review of community-based research: assessing partnership approaches to improve public health. Annual Review of Public Health. 1998; 19: 173 – 202.

Acknowledgements

Learn more about community-engaged research at ctsi.umn.edu

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