OHRP Conference—Participant Research

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Participatory Research

In September I attended the Office of Human Research Participants (OHRP) conference at the University of Michigan. Most of the conference was dedicated to reminding everyone of the Common Rule, research designations (Greater than Minimal Risk, Minimal Risk (Expedited or Exempt), and not research), and to expand upon, explain, and provide resources for the 2023 NIH Policy for Data Management and Sharing (DMS, 2023).

The other half of the conference was devoted to discussing participants in research, particularly as members of research teams, and how to include participants in research. Participatory research can be defined as a continuum, within which researchers and participants work together at various times, and to various depths to solve problems relevant to the population at hand. Social justice research, and community rights/advocacy research have long known the benefits of community-based research efforts. (see, for example the works of Miles Horton, Orlando Fals-Borda, and others in the action research field). Often participant-research is relegated to the "qualitative research designs" section of research methods texts. However, participant-research is not a research design, but, a paradigm or framework for understanding problem creation, research design and data collection, and the implications from research interpretation and results.

We first heard from Mona Hanna-Attisha, MD MPH, Professor Public Health, Professor of Pediatrics and Human Development, Director of Pediatric Public Health Initiative, Michigan State University. Dr. Hanna-Attisha has served as a pediatrician in the community of Flint, Michigan for many years, before and during the height of the Flint water crisis. As a pediatrician and researcher, she conducted many research studies to support policy changes at the state level. During her time advocating for Flint, she noted many researchers desiring to capitalize on the proximity of this crisis as a place of research, subsequently burdening the peoples of Flint, without enacting sustainable change. Her work resulted in the creation of the Center for Poverty Solutions, and the creation of an academic-community partnership to address these health inequities. The partnership works in concert with researchers to review and prioritize research initiatives. Dr. Hanna-Attisha partnered with Luke Shaefer, PhD, Professor of Social Work, Professor of Public Policy at the University of Michigan. Dr. Shaefer is now the director of Poverty Solutions.

Hayley S. Thompson, PhD, Professor in the Department of Oncology at the Wayne State University School of Medicine is the associate director for community Outreach & Engagement at Barbara Ann Karmanos Cancer Institute (an NIH funded cancer center), and the director of the Center for Health Equity & Community Knowledge in Urban Populations. Dr. Thompson's work continues to demonstrate an emphasis on community engagement to demonstrate the "meaningful involvement" of patients, caregivers, clinicians, and other health stakeholders "throughout the research process". This means involving the community in preparing for, conducting, and utilizing research. Interestingly, Dr. Thompson highlighted that their goals include having "community members and researchers collaborate in an interactive process of:

- Problem definition
- Problem solving
- Evaluation
- Building research and programmatic skills
- Developing tools
- Mobilizing new resources, and
- Broadening and deepening relationships

Dr. Thompson highlighted specific initiatives, including a 9-module research curriculum for community members to help them engage more deeply throughout the research process.

Several other speakers spoke of similar types of work in biomedical research within communities. The benefits of such work include a) better understanding of community needs in research; and b) building of sustainable relationships within the community. Community members become more engaged and informed through such efforts, are more willing to participate in research, and find that the research may have direct relevance to their community. Academic researchers and community members together benefit from such partnerships. The NIH and the OHRP fully support such efforts in improving health equity, and health outcomes for all.