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'STUMBLING' TO SUCCEED: CHALLENGES, OBSTACLES, AND ETHICAL DILEMMAS IN HUMAN PARTICIPANT RESEARCH (Panel)

Abstract or Résumé:

Research involving human participants can be the most creative and rewarding engagement, also distinguished by a wide range of methodologies. However, it comes with its own challenges related to ethics, technology, administration, institutional regulations, and the effective dissemination of findings. A group of researchers from Canada and the U.S. will discuss some common 'stumbles' in human participant research, including bias in quantitative data sets; the responsibility of disabled scholars for protecting participants and themselves; reconciling multilingual lifeworlds with western approaches to research and publishing; nurturing 'slow science' among emergent scholars; and overcoming institutional gaps in support for community-based research.

1. Panel Description

Even the most successful researchers have experienced stumbles and rough landings, but we rarely provide opportunities to discuss and learn from them. This panel stands to address some of these stumbles in community-based research involving human participants. Obstacles can originate from administrative and organizational issues; be rooted in ethical dilemmas; and stem from complex cultural contexts, to name just a few. Deriving from their own experiences as LIS researchers, educators, and mentors, the panelists from Canada and the U.S. will offer insight and analysis and introduce solutions and ways of coping. The panel will actively engage the audience in both discussion and problem-solving.

As a computational social scientist, who engages regularly in mixed methods analyses, **Tawfiq Ammari** will discuss technological and ethical biases engendered in datasets, how they are collected, and how people understand them. Using several examples, Ammari will address data collection in general and in marginalized communities in particular, as well as biases in data used in large computational models. As more and more public interfaces are closing to academic access, complicating data collection from social media sites, academics must find new ways of approaching it. One way is to consider asking people for their social media data. However, data

collection becomes especially challenging when we work with marginalized communities because of the need to anonymize discussions on social media channels while still using these data in computational models. Although all computational models have biases, they are discussed more rarely compared to subjectivity in qualitative methods.

As a scholar of health information behavior and practices who is chronically ill and disabled, **Kaitlin Costello** will address the following questions: "What are the implications of 'nothing about us without us' for the researcher and participants?" More specifically, how do we engage with personally meaningful research, while acknowledging and processing our own emotions and experiences, when we are a member of the communities with whom we work? How do we engage in participatory research while reducing harm to both researchers and participants? How do we work within and beyond an academic system that is inaccessible to most scholars with disabilities and not accommodating of our needs? And what implications does this have for knowledge building in LIS, and what kinds of practical and methodological leaps can LIS make to meet disabled scholars where we are?

Keren Dali will discuss some obstacles experienced by researchers who work with migrant and multilingual communities. She will examine cultural and linguistic bias often embedded in ethics protocols required by universities for engagement with human participants and its effect on participant recruitment. Established to safeguard the rights of participants and protect them from harm, abuse, or mistreatment, protocols are often designed with western cultural and linguistic assumptions in mind. The sheer volume of documentation required to be read prior to research participation can be intimidating, even if translated into community languages; the wording of "risks" and "dangers" to one's "well-being," derived from medical research and often non-applicable to social sciences, may be frightening, especially for individuals who are not entirely comfortable in the social environment around them and not familiar with the inner workings of academia. This results in the study documentation that disincentivizes the very participants whose voices we try to elevate. Dali will also examine the barriers to publishing research that uses non-English languages sources for framing and literature review. These sources, irrespective of their actual quality, are often not recognized as valid if reviewers do not read the respective languages and are not familiar with the scholarship originating outside of the English-speaking realm.

Heather Hill will turn her attention to so-called slow science in the context of community-engaged research by focusing on her experience teaching qualitative research methods to Ph.D. students and supervising their work. A good dissertation is a done dissertation, but what about students who are interested in doing deeply engaging research while also being under the constraints of a limited funding period? Students who are interested in community-engaged research, or research that requires significant reflective work, face pressures to rush or speed up a process that is not, and cannot be, fast. Hill will focus on how to support students in this type of work and outline some of the challenges they experience around timelines, progression requirements, funding, and the pacing necessary for these types of projects.

Charles Senteio will focus on the barriers to funding, executing, and disseminating community-engaged research, noting that, while universities state that they value 'community engagement,' they have not yet revised the standard research processes, guidelines, or metrics to accommodate

this work. Senteio will draw on the following examples: (1) Fair and timely compensation for community partners, including international collaborators; (2) Challenges of getting community-engaged work funded, especially when it focuses on Black/Brown 'hard to reach' populations; (3) Challenges of disseminating community-engaged work, such as reviewers' outsized scrutiny of sample size and the recruitment success (using an example of Black participants in Flint and Detroit, MI); and (4) how to achieve recognition (i.e., promotion) for conducting community-engaged work when traditional metrics for quality and productivity, such as the number of publications in high-quality journals and books and book chapters published in high-quality presses do not account for the 'value' of building and nurturing of the longitudinal relationships necessary for community engagement over time. Senteio will also share his experience overcoming these obstacles.

At the outcome of this panel, the audience will become more aware of and alert to the ethical issues related to human participant research; introduced to various methodological, procedural, researcher-oriented, and population-related aspects that can hamper community-engaged research; meet likeminded individuals interested in improving impactful research that gives voice to under-represented community members; and take away practical guidance and solutions for approaching dilemmas and resolving problematic issues.

2. Panel Structure (90 min)

- The panel will begin with the introduction of the unifying theme and the panelists – 5 min.
- Each presenter will provide a pecha-kucha style impactful introduction to their topic, stating the problematic issue(s) to focus on 6 min 40 sec x 5 panelists = approx. 35 min
- Quick Q&A will follow the talks – 5 min. At the end of the Q&A, each panelist will introduce a scenario relevant to their presented topic/issue and invite participants (divided into breakout rooms) to participate in finding a solution or debating a way forward. The outcome of each group discussion will be recorded using Padlet or another similar technology; panelists will curate their respective groups and be responsible for summarizing the group activity for the entire audience when everyone re-assembles in the general room. – 25 min.
- The general discussion of small-group outcomes will complete the panel – 20 min.

3. Panel Participants

Tawfiq Ammari is an assistant professor at the Rutgers University School of Communication and Information. His research lies at the intersection of Social Computing, Data Science, and Science, Technology, and Society Studies (STS) and focuses on the interplay between technological and social role change. Specifically, he studies how large societal shifts, such as changing norms around masculinity, are associated with online interactions and social movements.

Kaitlin Costello is an associate professor in the Department of Library and Information Science at the Rutgers School of Communication and Information. Their research examines how people look for, assess, use, and disclose health information, especially online. They also study methodology and qualitative, feminist, and participatory research practices in the field of human information behavior.

Keren Dali (Moderator), is an associate professor at the Research Methods & Information Science Dept., University of Denver. With her work funded and awarded distinctions in both Canada and the U.S., she focuses on disability and workplace equity; reading and leisure practices of multilingual adults; social work and LIS, and humanistic pedagogies.

Heather Hill is an associate professor in the Faculty of Information and Media Studies at the Western University. Her research focuses on accessibility and disability in libraries and policy. Additionally, she brings her experience working on research ethics boards and teaching and mentoring PhD students doing qualitative research.

Charles Senteio is an associate professor in the Department of Library and Information Science at the Rutgers School of Communication and Information. His research focuses on health equity, examining how intersecting identities such as race, ethnicity, and sexual identity and orientation impact perceptions that influence care decisions. He uses community-engaged approaches in his use of mixed methods to describe barriers and facilitators to equity.