Catalyzing Community and Stakeholder Engagement (CSE) in Research: Perspectives from Scientist and Stakeholder Experience

Siuy Chen, Sarah K. Brewer, Robert Sege, Aviva Must, Nadia Prokofieva, Thomas W. Concannon, Alice Rushforth and Lisa Welch

1Tufts Clinical and Translational Science Institute, Tufts University, Boston, MA; 2Institute for Clinical Research and Health Policy Studies, Tufts Medical Center, Boston, MA; 3Tufts University School of Medicine, Boston, MA and 4The RAND Corporation, Boston, MA

OBJECTIVES/GOALS: Community and other stakeholder engagement (CSE) is critical for relevant and equitable clinical research, yet implementation poses challenges. This study delineates the perspectives of scientists and diverse stakeholders regarding facilitators and challenges in CSE, its perceived value, and their recommendations for successful CSE. METHODS/STUDY POPULATION: The Tufts CTSI Pilot Studies Program requires applicants to propose a plan for CSE while implementing the award, including which stakeholders (SHs)—community members, clinicians, and others affected by the research—will be involved and at what stages. This qualitative study assessed the experiences of both Principal Investigators (PIs) and SHs engaged in pilot projects from three cohorts of awardees (2019-21). Recruitment targeted one PI and one SH per project. Semi-structured interviews explored their CSE experiences, including facilitators, challenges, meaningfulness, perceived impact, intent to participate in CSE in future studies, as well as recommendations for funders, research support organizations, and investigators. Inductive consensus-based coding and thematic analysis was employed. RESULTS/ANTICIPATED RESULTS: Fourteen PIs from different pilot projects and a SH from five of these projects participated. Almost all PIs (92%) had over six years of experience, but two-thirds (67%) had little or no experience with CSE. Four SHs self-identified as representatives of community organizations and one as a clinician scientist. CSE was a “win-win” for both PIs and SHs, and all PIs intended to involve SHs in other research studies. Three facilitators were identified as fostering effective CSE (e.g., PI access to CSE expertise while conducting the project), while four challenges hindered it (e.g., limits on SH capacity and CSE funding). SHs advised scientists to build authentic, sustained relationships, and PIs and SHs provided three actionable recommendations for funders and research support organizations to deepen and expand CSE. INDUSTRY/SIGNIFICANCE: Perspectives of scientists and SHs regarding facilitators, challenges, meaningfulness, perceived impact, and intent to participate in CSE in future studies are valuable for enhancing the integration of CSE in research. This study identifies key facilitators and challenges and provides recommendations for effective CSE.

A “Blueprint” for Developing a Research-Community Partnership to Utilize Real World Data

Grace Cua, Jim Poole, Kathleen Diviaik, Frederica Malone, John O’Keefe, Tara Mehta and Marc Atkins

1University of Illinois at Chicago and 2NAMI Chicago

OBJECTIVES/GOALS: Real-world data (RWD) may offer insights into mental health treatment as usual and illuminate targets for implementation and translation. This requires strong research-community partnerships (RCP). In this presentation, we will highlight key components of an ongoing RCP in leveraging RWD to advance translational science. METHODS/STUDY POPULATION: The RCP was formed to develop an infrastructure for NAMI Chicago, a community-based organization that oversees a city-wide social services helpline, to support collection of RWD data to understand whether NAMI helpline support services and referrals meet callers’ emotional and physical needs. This RCP includes three entities: NAMI Chicago, UIC’s Center for Clinical and Translational Science’s Community Engagement and Collaboration (CEC) Core, and UIC’s Institute for Health and Research Policy’s Data Management Core (DMC). From a preliminary review of case notes, this case study details concrete examples that fit into Brookman-Frazee et al. (2012)’s RCP framework to illustrate the trajectory of this partnership through its formation, execution of activities, and sustaining NAMI Chicago’s data capacity. RESULTS/ANTICIPATED RESULTS: In the formation of this RCP, we identified our joint goal of creating a database infrastructure to link NAMI Chicago’s existing helpline data with a database co-created in REDCap through APIs. Based on the identified joint goal, we defined our roles/responsibilities that best aligned with our own individual expertise to execute the necessary operational processes. The RCP is currently executing the activities to create this data infrastructure. Barriers included delays in securing a computing environment and enablement with an established long-standing relationship between NAMI Chicago and CEC. Distal outcomes of this RCP include increasing NAMI Chicago’s capacity to systematically use RWD to better inform their practices and identify barriers in accessing social service resources in Chicago. DISCUSSION/SIGNIFICANCE: The identification of enablers, barriers, and the necessary operational processes and activities will outline a “blueprint” for other institutions and community organizations to successfully utilize RWD to understand mental health practices and advance translational research.

Progress in Community Health Partnerships Writing, Dissemination and Reviewer Learning Community for Community-Patient Authors and Reviewers (henceforth, PCHP LC)

Karen Calhoun, Tabia Akintobi, Al Richmond, N Glassman, Rosanna Barrett and Hal Strelnick

1Michigan Institution for Clinical & Health Research; 2Morehouse School of Medicine Prevention Research Center; 3Community-Campus Partnerships for Health; 4Samuel Gottesman Library, Albert Einstein College of Medicine; 5Progress in Community Health Partnerships Learning Community Workgroup Progress in Community Health Partnerships Editorial Team and 6Albert Einstein College of Medicine

OBJECTIVES/GOALS: The peer-reviewed journal Progress in Community Health Partnerships (PCHP) promotes health research partnerships to improve community health. PCHP’s Writing, Dissemination and Reviewer Learning Community Pilot aims to increase stakeholders writing and reviewing for greater relevance and diversity. METHODS/STUDY POPULATION: Led by PCHP’s Editorial Team, Morehouse SOM, Community-Campus Partnerships for Health (CCPH) and a community-academic Workgroup, the LC will guide stakeholders on scholarly writing and publish collaborative research. It builds on the 2017 Writing/Dissemination Learning Institute held by Morehouse, CCPH, and