SHIFT IN HOW RESEARCH IS CONDUCTED

Instead of conducting research on the community, research teams are increasingly conducting research with the community. There are many valuable contributions community partners can make to enhance a research study. Research teams can work with community partners to select research questions that patients care most about, include their feedback in study decisions, and share study results with relevant populations to improve health.

WHO ARE COMMUNITY PARTNERS?
Community partners (also referred to as stakeholders) can include anyone who has a voice to share in the research; patients, caregivers, policy makers, clinicians, advocacy groups, health system leaders, payers and others.

WHY DOES THIS MATTER?
The ultimate goal of research on individuals is to improve lives. Inviting the community to the research table and engaging them throughout the research process can help ensure we are asking the right research question(s), improve how we run the study, and keep patients at the center of our work.
In a natural experiment, researchers are not able to manipulate or control anything—instead, they closely watch what is happening in the real world to find out if treatment plans and programs that currently exist are actually helping people. This is different from other studies, such as clinical trials, where individuals are placed in either a treatment or placebo group by the researchers. Natural experiments allow us to study health information on a lot of people—much more than a more traditional research study. This means we can better understand if what may be helping a large group of people would also be the case for the greater good.

Not much has been done in this space but that’s where we come in! Our PaTH to Health: Diabetes study has engaged 6 patient partners, 10 community stakeholders, and 6 clinician stakeholders in a natural experiment that seeks to understand how often weight counseling is provided in the primary care setting to patients with or at risk of type 2 diabetes and if it’s improving weight and diabetes.

First, we recruited our diverse stakeholder group, which includes patients, clinicians, policy makers, and leadership from national professional organizations. We sought input from our partners in all phases of the study, i.e. selecting health outcomes most important to include in our study based on patient partners’ lived experience with diabetes, understanding clinical barriers to weight counseling from the expertise of our clinician stakeholders, and identifying appropriate outlets for sharing our study results. We maintained open and honest communication with our partners throughout study meetings, compensated them for their efforts, and created platforms for their voices to be shared and applied to our work, such as a patient-centered study website and newsletters. We also offered trainings and educational opportunities to overcome gaps in knowledge during specific research phases. Ongoing engagement evaluations provided an important opportunity to assess engagement activities and improve processes moving forward. Together, these approaches support meaningful stakeholder engagement in a natural experiment and we hope readers find the recommendations for replication in similar studies helpful in developing and implementing their own engagement plans.