

# CDS Connect Patient and Caregiver Partnering Panel



*We aspire to inspire CDS developers to take one more step to engage and partner with patients and caregivers*

## What is patient and caregiver partnering?

Patient partnering, patient engagement, and patient-centered care differ, though they are cousins. The literature on patient participation in treatment and care (patient engagement/patient activation) is established and growing.

The dynamic of partnering reflects inclusion and contribution to decision-making, not just at certain points in development, but continuously. We propose partnering done early, often, and throughout the CDS development lifecycle results in tools (such as shared patient-clinician decision-making visualizations and applications) that ultimately support providers in delivering evidence-based, patient-centered care.

## Lessons Learned: One More Step

- 1. Partnering/co-production is not for the faint of heart, exhausted, insecure, or self-centeredly ambitious. It's work, it's risky—but it is also rewarding.** Partnering/co-production rests on a foundation of trust, humility, respect for varied expertise, mutual coaching and mentorship, self-confidence, and curiosity. It's not about consultation, participation, or engagement – words used to describe situations where the project controls the contributions made by those outside its boundaries.
- 2. A shift occurs when newly partnering with patients and caregivers. Readiness for that change varies widely. That variation impacts results.** Administrators, researchers, developers, clinicians—often the “up party” in an unequal relationship—are not homogenous, the same. They vary. Perhaps we can group these perceived powerful into those that have already embraced partnering and sharing in decision-making and those who haven't. Some have existing partnering perspective, know they have a problem to solve that requires expertise they don't yet have access to, and appreciate the expertise of life literacy and lived experience. Some don't. Some have budgeted for engagement and partnership, have self-confidence, aren't threatened by change, are prepared to change. Some aren't.

The members of the public exist on a continuum as well. Researchers and developers may benefit from understanding the variation among us, the public. We are not homogenous, the same. We have varied comfort and understanding of our lived experience, varied communication skills, and varied knowledge of medical terms and systems. Some of us are more networked than others, have more time to devote to advocacy, more desire.

Some have transportation to events or high-speed internet access. Some have dependent care responsibilities, and some don't. Some have hutzpah, self-confidence, or curiosity, and some have less.

- 3. Appreciating the diversity, the continuum, meeting people where they are, can overwhelm us. One size does not fit all.** Assuming curiosity, discomfort with the current state, the time, some funding, and existing trustful relationships, we can take many steps. By we, I mean any of us—researchers, clinicians, developers, the public, funders. We could:

- Spend 15 minutes each week journaling what works and what doesn't for any partnerships with other stakeholders in your research universe. Self-assess where you and yours live on the continuums of partnership and co-production. Self-examine satisfactions—or not—with the implementation of your current findings. Share widely wherever you meet peers.
- Budget for engagement and partnering/co-production early—if not dollars, then in pro-bono time. Time is not free for anyone.
- Build on current trusting relationships with peers and stakeholders who have partnered. Find inspiration there. Experiment with them.
- Embrace failure. Partnering/co-production is messy and fraught. I've learned more from what didn't work than did. Adjust; try something else.
- Spend at least 50% of your time with partners with mouths closed, ears open. They know stuff you don't.
- Hone your ability to identify questions and issues that your current team hasn't yet solved. Could people with different abilities, circumstances, conditions, and/or expertise offer a door-opening perspective? Formulate questions they could answer. Have courage.
- No matter how good you are in your bubble of expertise, or in professional or lived experience, seek and accept coaching about co-production. If you've had some success with partnering/co-production, budget time for mentorship.