

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.

How could developers partner with patients and caregivers?

There is a role for patient and caregivers in the development of all levels of artifact development. When integrated within the research and development team, engaged patients and caregivers can ask questions and provide perspectives that keep efforts focused on making impacts in patient lives. When included in user research, participatory design, or user-testing activities, their input helps define and refine the resulting prototypes and software applications that are piloted and implemented into our health systems.

When might developers consider partnering?

At all stages of the CDS development lifecycle, there is a role for partnering with patients and caregivers. Co-production can happen at all phases and stages, from defining and prioritizing research through dissemination of the work up through implementation and refinement.



What are some of the ways patients might partner?

- Share the questions and decision people make to live safely and well
- Share their lifeflows as a patient and/or caregiver
- Identify and describe factors that impact patient and care giving decision making (e.g., cost of treatment)
- Help prioritize needs, development outcomes, and measures of impact of CDS and CDS artifacts
- Contribute to the development of personas and use cases
- Share feedback on impact of piloted or implemented CDS artifacts
- Disseminate the work through their patient and care giver advocacy networks
- Provide content, requirement, and design reviews of CDS and CDS artifacts under development
- Be a member of a patient expert panel, focus group, or working group

What resources are available for partnering?

One of the challenges identified by our panel members was knowing what resources were readily available when considering integrating patients and caregivers into their efforts. Members identified and shared a variety of resources (including local, national, and governmental efforts and toolkits), as well as professional and commercial entities. Some of those recommended included:

- Rare Patient Voice LLC
- Patient Family Advisory Network
- Society of Participatory Medicine
- Saavy Coop
- PCORI Ambassador Program
- CMS Person & Family Engagement Toolkit
- WEGO Health
- Local Patient Family Advisory panels

Lessons shared about partnering

It is a process, not a few points in time – Partnering is iterative and on-going.

Budget, and budget upfront – Make partnering a part of overall research and development plans.

Do, try, learn, and try again – There is no perfect way to partner.