

# 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*

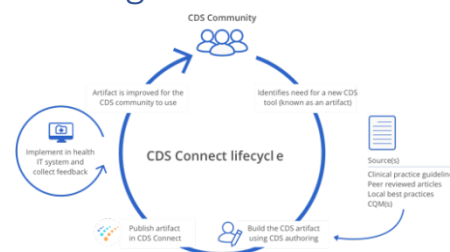
## What is patient and caregiver partnering?

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 might 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.



## 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

## Ideas and questions to explore

Over the course of the four sessions of the panel, members shared related questions and ideas on CDS development and patient partnering. The comments below illustrate the breadth of the topic overall and the opportunities that remain to be explored.

- Standards and interoperability impact how patients' and caregivers' needs are met with CDS.
- The patient is where the current "silos" collide - policy, clinical evidence, funding, standards, and cost.
- Build personas to illustrate the impact of income/insurance on clinical decision-making.
- In the future, showcase examples of successful partnering.
- What makes partnering different from user-centered design processes and methods?
- How can we best communicate risk to patients?
- How can social determinants of health and/or patient preferences be integrated into CDS?
- When testing or implementing an artifact, what mechanisms can be put in place to ensure the patient, caregiver, and clinician feedback loops back to development? How can we measure the feedback's impact?
- What statistics might most meaningfully measure the impact of a CDS artifact? Should it be file downloads from CDS Connect, counts of locations of use, or number of patients impacted?
- Do these partnering resources provide training to their patient advocates? Is there training available for the development teams about partnering?
- How can I start developing a long-term partnering relationship? How do I reach out to frame our project's needs?