



AGENCY FOR HEALTHCARE RESEARCH AND QUALITY



April 2022 CDS Connect Work Group Call



CDS Connect

Agenda

Schedule	Topic
3:00 – 3:02	Roll Call, Michelle Lenox (MITRE)
3:02 – 3:05	Review of the Agenda, Maria Michaels (CDC)
3:05 - 3:35	Roundtable and Discussion on Partnering Experience: Amy Price (Stanford); Danny van Leeuwen (HealthHats). Moderated by MITRE.
3:35 – 3:50	Prioritize next steps in patient partnering (MITRE)
3:50 - 3:55	What's New with CDS Connect (MITRE)
3:55 - 4:00	Open Discussion and Close Out, Maria Michaels (CDC) <ul style="list-style-type: none">• Open discussion and announcements• Concluding comments, review next steps and adjourn

Objectives

- Review progress on patient partnering
- Share experiences of partnering with patients and caregivers
- Prioritize approaches for establishing best practices for patient involvement in CDS development and implementation
- Share new features and resources available for CDS Connect

Past Discussions on Patient and Caregiver Partnering



- March 2021 – Partnering with Patient and Caregiver Community to Develop CDS (Site Changes)
- April 2021 – Person-First Safe Living in a Pandemic (Patient Partnering)
- Summer 2021 – Patient Partnering Panel
- December 2021 – “One More Step” and AHRQ Grantee Roundtable
- January 2022 – ACTIVATE and co-production
- April 2022 – Partnering Perspectives/Patient Editors/Prioritization

Patient Partnering Panel: Draft Content

Overview

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 related. 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 patient 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 lifeworlds 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 resource 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
- Saavy Coop
- WEGO Health
- Patient Family Advisory Network
- PCORI Ambassador Program
- Local Patient Family Advisory Panels
- Society of Participatory Medicine
- CMS Person & Family Engagement Toolkit

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.

<https://cds.ahrq.gov/cdsconnect>

Lessons Learned

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Lessons Learned: One More Step

1. Partnering/co-production is not for the faint of heart, exhausted, insecure, or self-centrally 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, and 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, 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, 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-examine where you and your lives live on the continuum 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, pro-bono time. Time is not free for anyone.
- Build an 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.
- None your ability to identify questions and issues that your current team hasn't yet solved. Could people with different abilities, circumstances, conditions, expertise offer a door-opening perspective? Formulate questions they could answer. Have courage.
- No matter how good you are in your bubble of expertise, 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.

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To Explore

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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 best to 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 do a start developing a long-term partnering relationship? How do I reach out to frame our projects needs?

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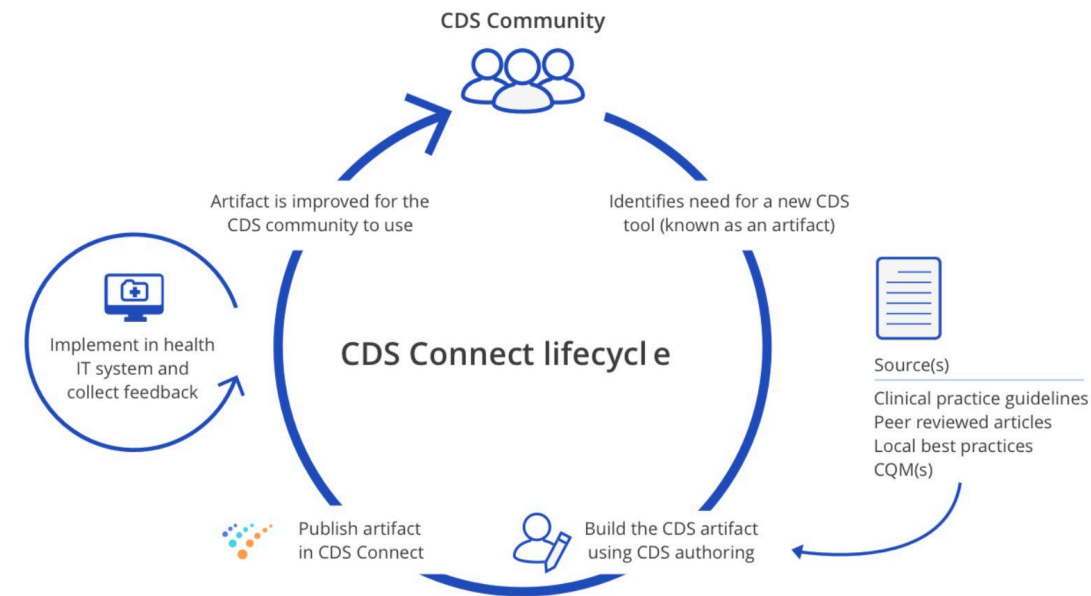
“One More Step” Campaign

Objective

- During this CDS Connect project year, gather lessons learned from each point of the clinical decision support development lifecycle on how standards/methods/best practices can better support patient involvement

Lessons Learned from Patient Partnering Panel

- Patient partnering in theory is well accepted, but it isn't happening in practice
- It is necessary to ensure resources are widely known and accessible
- Several levels of involvement can occur in development and implementation of clinical decision support



December WG Themes

- Identification of patient partners
 - ▶ Reflecting diversity and characteristics of the population of interest
 - ▶ Recruiting of a larger pool of “citizen scientists”
 - ▶ Addressing the “digital divide”
 - ▶ Establishing common language in communicating the importance of and needs for partnering
 - ▶ Mentoring newer patient representatives
- Early and continued patient involvement
- COVID challenges and new virtual opportunities
- Important considerations
 - ▶ Social norms
 - ▶ Trust
 - ▶ Sharing one's story early
 - ▶ Individual needs or preferences

Dr. Amy Price – Stanford AIM Lab/BMJ Patient Editor



- **Goal(s) of research:** To mentor and to build bridges between clinicians, researchers, and patients to co-produce research that improves healthcare
- **Goals(s) as patient advocate:** To mentor patient advocates and students in co-creating research
- **Desired impact:** Open door for innovation and implementation
- **Share your experience working with patients in development and/or implementation:** Work from where you are with what you have, it will make a difference. Work in transparency, respect and empathy as they will create a climate for curiosity, innovation, and unexpected but welcome solutions.
- **Lessons learned:**
 - ▶ Earlier involvement; better planning; role clarity; positive constructive feedback; adequate funding and celebrating even the small wins; we all need to belong.
 - ▶ Life is too short to live in the past—learn from failure, it is an event not an identity, other opportunities come like waves, if you miss one, catch the next one.

Danny van Leeuwen – Health Hats



- **Goal(s) of research:** Learn on the journey toward best health
- **Desired impact:** Increase seats for people with lived experience at the tables of healthcare governance, operations, design, learning
- **Share your experience working with patients in development and/or implementation:** RN; clinical manager; QM leader, EMR implementation consultant; and Board of Governors of PCORI
- **Lessons learned:**
 - ▶ Partnering is not for the faint of heart.
 - ▶ Include caregivers.
 - ▶ Meet people where they are.
 - ▶ Experiment.
 - ▶ Build on existing, trusting relationships.

Perspectives on the Partnering Experience

- Why is the complexity of partnership worth it?
- What was your best experience being onboarded and mentored on a new team?
- How do you determine appropriate compensation for a patient caregiver consultant? A patient caregiver consultant asks to be paid, how is this managed? What have you seen happen?
- How do we create and maintain respect in conflict?
- What changes have you seen made in CDS as a result of patient-caregiver partnerships?



DISCUSSION:

**PRIORITIZE APPROACHES FOR ESTABLISHING
BEST PRACTICES FOR PATIENT INVOLVEMENT
IN CDS DEVELOPMENT**

Approaches

- Finalize and disseminate Patient Partnering Panel content
 - ▶ Create a new resource page or new FAQ entry on CDS Connect
 - ▶ Include reference in Repository User Guide
- Invite and share lessons learned from outside the WG
- Provide insights to other efforts or venues (e.g., conference submissions/peer reviewed publications)



Patient Partnering Resources

- Identification of toolkits and framework for partnering
- Organizations to recruiting patients and patient advocates from
- Work groups/discussion groups sharing partnering work and best practices
- Best practices for communicating with leadership on the value of patient partnering
- Tools and support for championing patient partnering within one's organization
- Inclusion of patient partnering in funding calls (RFI/FOA/proposals)
- Financial support for patient partnering activities
- Best practices for communicating with patients and partners on CDS and research/development process
- Identification of organizations that have excelled at partnering/panels
- Examples of 'just in time' partnering developing into long-term partnerships



WHAT'S NEW WITH CDS CONNECT

Sam Carrillo and Julia Afeltra, MITRE

Updates and New Features



Authoring Tool

- Users must now agree to CDS Authoring Tool terms and conditions
 - ▶ Users will be asked to accept the terms and conditions upon first login
- Preparation for migration to a new server environment
- Ongoing refactoring to improve maintainability and reusability

Repository

- Drupal 9 security updates
- Upgraded memory on servers
- Working to restore MeSH taxonomy browsing
- Creating alerting solutions when artifact author has requested review to notify CDS Connect admin team
- User guide documentation development continues
- Coordinating with NORC on Clinical Decision Support Innovation Collaborative (CDSiC) site on development and deployment

Artifacts

- Ongoing review of new and updated artifacts contributed to the Repository
- Updated CDS Connect project artifacts IGs and CQL
 - ▶ Reflect updated evidence in artifact sources
 - ▶ Align more closely with FHIR Clinical Guidelines CQL guidance
 - ▶ *NOTE: These changes are not yet published in the Repository*

ANNOUNCEMENTS, OPEN DISCUSSION AND CLOSE-OUT

Maria Michaels
Centers for Disease Control and Prevention