

## December 2021 CDS Connect Work Group Call



## Agenda



Schedule	Topic
3:00 – 3:02	Roll Call, Michelle Lenox (MITRE)
3:02 – 3:05	Review of the Agenda, Michelle Lenox (MITRE)
3:05 – 3:10	Kick-off "One More Step" in Patient Partnering, Michelle Lenox (MITRE)
3:10 – 3:50	Roundtable discussion with AHRQ grantees – Chris Harle (University of Florida), David Dorr (OSHU), and Patty Dykes (Brigham and Women's Hospital) Moderated by Danny van Leeuwen (HealthHats)
3:50 – 3:55	What's New with CDS Connect (MITRE)
3:55 – 4:00	Open Discussion and Close Out, Michelle Lenox (MITRE)  Open discussion and announcements  Concluding comments, review next steps, and adjourn

## **Objectives**



- Discuss this year's patient partnering effort, building on last year's patient partnering panel
- Learn about other AHRQ clinical decision support research
- Discuss topics of interest to members relating to opportunities for CDS Connect



## KICK-OFF "ONE MORE STEP" IN PATIENT PARTNERING

Michelle Lenox, MITRE

## 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 partnerine 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

#### What are some of the ways patients might partner?

- Share the questions and decision people make to live safety 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 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:

- Saavy Coop WEGO Health
- - Patient Family Advisory Network PCORI Ambassador Program Local Patient Family Advisory Panels
- CMS Person & Family

#### 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-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, 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,

- 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-products. Self-examine satisfactions, or not, with the implementation of your current findings. Share widely wherever you
- Budget for engagement and partnering/co-production early. If not dollars, pro-bono time. Time is not free for
- Build on current trusting relationships with peers and stakeholders who have partnered. Find inspiration there.
- Embrace failure. Partnering/co-production is messy and fraught. I've learned more from what didn't work than did.
- 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, expertise offer a door-opening perspective? Formulate questions they
- 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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Rare Patient Voice LLC 

Patient Family Advisory Network Society of Participatory Medicine CMS Person & Family 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 illustate 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

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

## "One More Step" Campaign

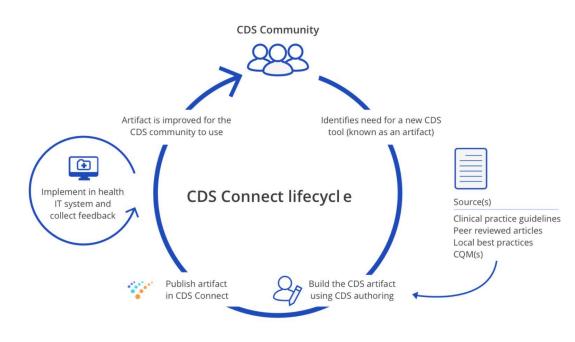


#### **Objective**

 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





# ROUNDTABLE DISCUSSION WITH AHRQ GRANTEES ON PATIENT INVOLVEMENT LESSONS LEARNED

Danny van Leeuwen, HealthHats

## Chris Harle – Scaling Interoperable Clinical Decision Support for Patient-Centered Chronic Pain Care



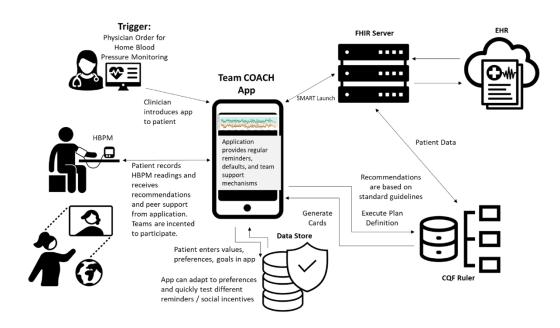
- Goal: Make it easier for clinicians and patients to gather key information and talk about the pros and cons of different pain treatment options.
- Impact: Improve pain and function for patients with chronic pain.
- Experience working with patients: We are partnering with patients to adapt the system for local use, and to what works well, and what can be improved in implementation.
- Lessons learned: Collecting and carefully mixing patient, clinician user, and information technology experts' feedback is key.

## David Dorr and COACH Tool



- Goal: Develop a patient-facing clinical decision support tool (using SMART on FHIR and CQF-RULER) for high blood pressure management.
- **Impact:** Provide guidance to patients with hypertension and promote patient agency in hypertension care, improving outcomes.
- Experience working with patients: We interviewed and surveyed > 500 hypertensive patients to assess attitudes towards CDS, asking them for input regarding trustworthiness of information presented and for priorities for care. We also built the COACH tool based on patient/provider input in accordance with agreed-upon clinical practice guidelines for high blood pressure.
- Lessons learned: Patients prefer more complete and socially related information to be presented to them and consider managing their blood pressure a high priority. We are applying for continuation grants which will include hands-on testing of the COACH tool with patients.

### **Coach Technical Diagram**



## Patti Dykes and ASPIRE\*



**Goal:** To develop and integrate fall prevention decision support into routine primary care practice **Impact:** 

- Guide primary care providers to the most effective fall prevention strategies for an individual patient
- Engage patients and family in fall prevention decision-making



#### **Experience working with patients**

- Completed 18 Interviews with Patients/family to inform ASPIRE user requirements (Urban/Rural)
- Conducting clinic observations/post-visit interviews

#### Lessons learned

- Balancing needs of urban vs. rural
- COVID
  - Pivot to zoom works!
  - Urban vs. rural social determinants
- Patient education materials
  - Leveraging existing content vs. "reinventing the wheel"
  - No single way patients prefer to receive information
    - Multiple modalities: Video/pdf
    - Patient stakeholder feedback on format and content

## **Discussion Questions for Grantees**



- Did the patient experience meet your expectations?
- What would you have done or wanted to do, if the circumstance was different?
- How did the phase of development/implementation impact how easy or hard it was to involve patient-caregiver community partners?
- Once you identify patient-caregiver-community partners, what support do they need? What support does your team need? ... Do you need?
- How has the business case for patient-caregiver-community partnering been shared or challenged in your organization's hierarchy?
  - For whom do you need to make a business case?
- Do you know of, or participate in, a community of people with experience with partnering? Would such a community be helpful?

## **Discussion Questions for All Attendees**



- How would you recognize success with the partnering? If you could accomplish one thing with partnering, what would that be?
- How has the business case for patient-caregiver-community partnering been shared or challenged in your organization's hierarchy?
- Once you identify patient-caregiver-community partners what support does your team need? ... Do you need?

## **Next Steps**



- Share Patient Partnering write-ups as part of special email update, including posting to CDS Connect
- Build on lessons learned discussed today, including how to share via CDS Connect
- Send your lessons learned via the format of template slide (Slide 14)

## Patient Partnering Lessons Learned



- Goal(s) of research: [Stated in lay terms]
- Desired impact: [Stated in lay terms]
- Share your experience working with patients in development and/or implementation [Either what you did or would have done if the circumstance was different]
- Lessons learned: [What change/s would have made greater patient involvement feasible]



## WHAT'S NEW WITH CDS CONNECT

Matt Coarr and Chris Moesel, MITRE

## **Updates and New Features**



#### **Authoring Tool**

- Added XML ELM files to artifact downloads
- Updated Docker build script for improved efficiency
- Updated Node and dependency libraries
- Ongoing refactoring to improve maintainability and reusability

#### Repository

- Drupal 9 is deployed and running in production
- Ongoing work on memory issues due to MeSH taxonomy
- Working with AHRQ/NORC on distributed development plans for merging in learning path and CEDAR content
- Troubleshooting artifact view REST endpoint issues

Link to CDS Connect: <a href="https://cds.ahrq.gov/cdsconnect">https://cds.ahrq.gov/cdsconnect</a>



# ANNOUNCEMENTS, OPEN DISCUSSION, AND CLOSE-OUT

Michelle Lenox, MITRE