

Final Report

The Patient-Centered Clinical Decision Support Learning Network: Improving the Dissemination of PCOR in Patient-Centered Clinical Decision Support

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Structured Abstract

Purpose: Patient-centered outcomes research (PCOR) informs better health decisions. However, there is a gap between the generation of PCOR findings and incorporation of PCOR into clinical decision support (CDS). CDS can make PCOR findings accessible and actionable, but many barriers to the dissemination of PCOR in CDS exist. The PCOR Clinical Decision Support (PCORDS) Learning Network, later renamed the Patient-Centered Clinical Decision Support Learning Network (PCCDS-LN or “the Learning Network”), was created as a multistakeholder collaborative to address barriers and facilitators, formulate recommendations, and take action to improve the adoption and use of PCOR-based CDS.

Scope: The project convened and operated a multi-stakeholder Learning Network to identify barriers and facilitators, formulate recommendations, facilitate collective action, monitor progress, and foster sustainable infrastructure.

Methods: The Learning Network used multiple methods to advance PCCDS, including hosting theme-based annual meetings; a website; workgroups targeting key areas; webinars; publication of white papers, reports, and manuscripts; and presentations and posters at relevant conferences and events.

Results: The Learning Network identified key barriers and facilitators to the dissemination of PCCDS, characterized the CDS life cycle and CDS ecosystem, advanced a widely adopted definition for PCCDS, improved understanding of technical and design requirements for PCCDS, introduced an action plan for the use of PCCDS to address the opioid crisis, advanced methods for improving trust in CDS artifacts, and proposed sustainable mechanisms for improving the adoption and use of PCCDS.

Keywords: Patient-Centered Clinical Decision Support, PCCDS, Clinical Decision Support, CDS, CDS Standards, Learning Networks

Purpose

The Patient-Centered Outcomes Research (PCOR) Clinical Decision Support (PCORCDS) Learning Network was conceived to convene and foster collaboration between public and private stakeholders to advance their overall capability to incorporate PCOR findings into care processes using clinical decision support (CDS). There were four specific aims:

Establish the Learning Network.

In the first year, convene, charter, implement, and initiate operations of a broad and highly inclusive CDS Learning Network, to include multiple stakeholders with an interest in disseminating and enabling PCOR findings through CDS.

Identify barriers and facilitators, and formulate recommendations for enabling PCOR findings in clinical workflow using CDS.

Develop recommendations and pursue activities designed to catalyze, facilitate, and coordinate progress towards incorporation of PCOR findings into CDS. Progress included implementing a web-based collaboration and publication hub, webinars, briefs, collaboration with professional societies and standards organizations, and creation of a repository containing examples of successful dissemination initiatives.

Monitor, evaluate, and adapt the Learning Network to optimally support the dissemination of PCOR findings into clinical workflows via CDS.

Monitor and measure the effect of the Learning Network on the dissemination and use of PCOR findings in CDS tools and adapt its activities to increase effectiveness based on these findings.

Develop a sustainability plan for ongoing operations of the Learning Network.

Building on the lessons learned from the initial roll-out, Learning Network stakeholders would develop actionable strategies that highlight the network as a valuable resource and provide for ongoing operations.

Scope

Background

PCOR can give patients and providers the power to make informed health decisions and a greater voice in assessing the value of healthcare options. The rapid growth in PCOR funding and the knowledge generated by PCOR initiatives can empower patients, families, and providers with high-quality, evidence-based knowledge tailored to individual needs; however, there is a gap between generating the PCOR findings and the means for those findings to be effectively disseminated and incorporated into clinical care.¹

CDS provides patient-specific information, enabled by health information technology (IT), to clinicians, patients, or other individuals to enhance health and healthcare.² It is a process for enhancing health-related decisions and actions with pertinent, organized clinical knowledge and patient information to improve health and healthcare delivery. Information recipients can include patients, clinicians, and others involved in patient care delivery, and the information delivered can include clinical knowledge and guidance, intelligently processed patient data, or a mixture of both. Information delivery formats can be drawn from a rich palette of options that includes data and order entry facilitators, filtered data displays, reference information, alerts, and others.³ The availability of CDS interventions has grown with the adoption of certified electronic health records (EHRs) as part of the federal Meaningful Use program.⁴ CDS now provides an opportunity to deliver PCOR findings directly to patients or providers in daily workflow, where those findings can be made actionable in a clinical care and patients' daily routines. Yet numerous barriers persist and must be overcome for PCOR findings to be broadly applied via CDS. These include:

- limited expertise with interpreting and embedding PCOR findings into CDS;
- the lack of widely adopted standards for representing and sharing clinical knowledge in a computable form;
- the lack of forums for stakeholder engagement;
- the lack of a model for creating and managing knowledge repositories in both human-readable and unambiguous executable form;
- the absence of a central repository or knowledge resource where computable guidelines can be shared and stored;
- poor support for CDS in commercial EHR systems;
- challenges in integrating CDS into the clinical workflow; and
- limited understanding of organizational and social issues relating to CDS.

The Learning Network was designed to address these gaps through the creation of a stakeholder supported collaborative to identify barriers and facilitators, formulate strategy and recommendations, and coordinate actions to drive the adoption and use of PCOR supported CDS.

Context and Participants

The Learning Network was conceived as a multistakeholder collaborative that would convene and facilitate efforts to address the barriers and facilitators to the dissemination of PCOR through CDS. During its period of performance, the Learning Network identified a variety of key stakeholder groups⁵ and the roles⁶ they played in the CDS ecosystem.

Stakeholder entities included clinicians, payers, patients or patients advocates, providers, standards organizations, health IT and knowledge vendors, medical device makers, federal agencies, foundations and research institutes, quality support organizations, organizational governance bodies, accrediting and licensing bodies, health information exchanges and data organizations, and professional societies.

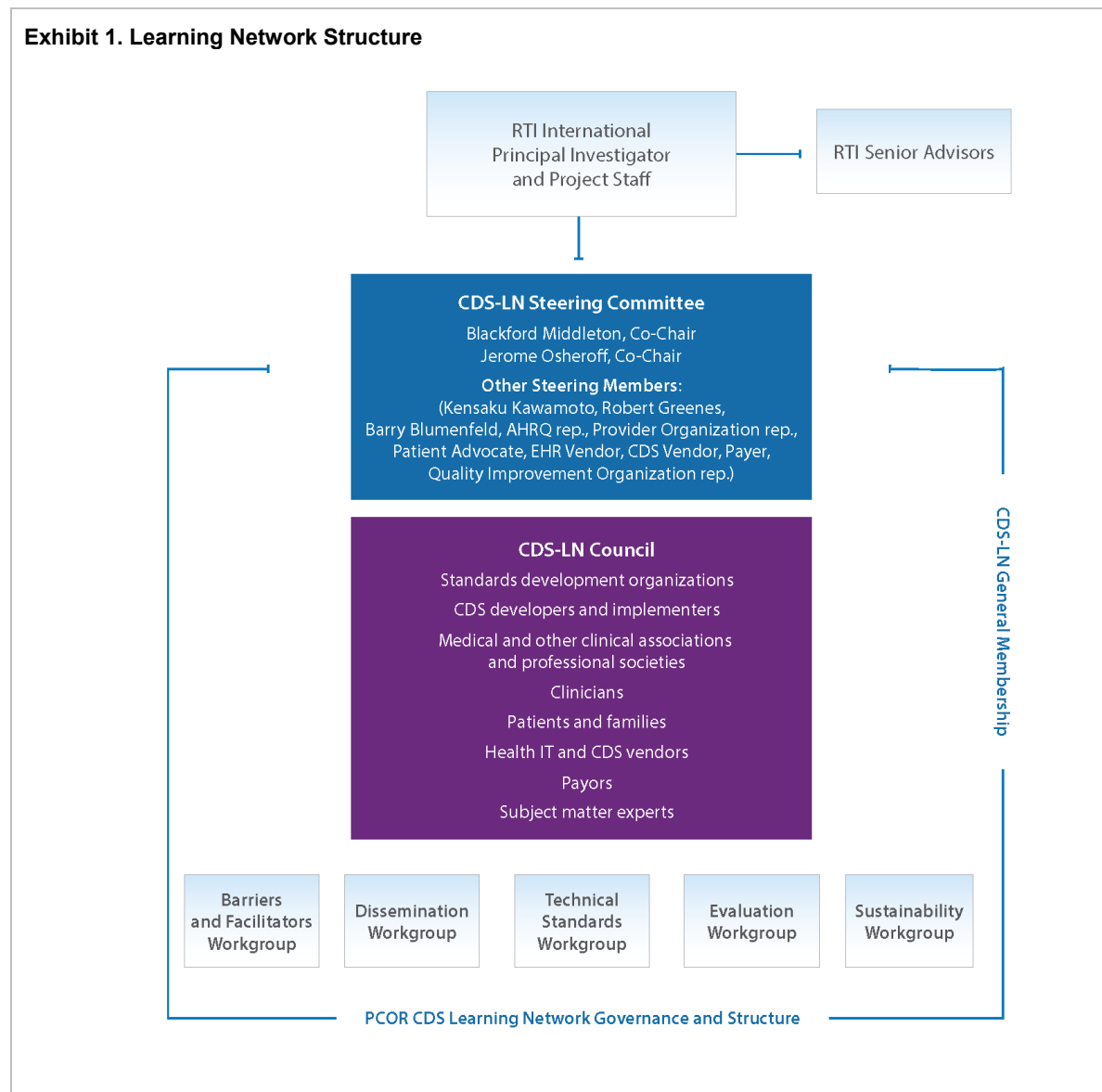
Within each of these stakeholder groups, we identified a variety of roles that individuals or organizations could play in the CDS "ecosystem" (note that the stakeholder group and role are often synonymous, but not always). The roles included clinician, payer, patient, patient advocate, provider, standards developer, evidence-based researcher, quality improvement analyst, policymaker, population health end-user,

knowledge author, knowledge curator, knowledge distributor, knowledge engineering professional, and standard-based application developer.

Methods

Study Design

The Learning Network proposed two key governance bodies to oversee and guide for its activities at its onset, composed of multiple stakeholder groups relevant to the dissemination of PCOR findings through CDS. This included a **Steering Committee (SC)** and a **CDS-LN Council**, later renamed the **Advisory Council (AC)**. The Intended goals of the of the SC included strategic advice and overall project governance. The SC was conceived as a larger body (25 or more individuals) to advise and recommend actions in the strategic areas identified, confirm webinar topics, suggest website focus and content, suggest commissioning of workgroups, assist in choosing stakeholders to include in workgroups, and identify key factors for consideration by workgroups. Exhibit 1 illustrates the Learning Network’s initial approach to governance as well as workgroups anticipated at the start of the project.



Data Sources and Interventions

The intent of the Learning Network design was to collect data as a byproduct of the interventions and activities the Learning Network convened and led. The proposed interventions included website and social media analytics, surveys from webinars and annual conferences, and qualitative feedback from stakeholders.

Environmental Scan and Bibliography

The environmental scan was proposed to create an understanding of the current state of affairs, barriers and facilitators, and recommendations for the incorporation of PCOR findings into CDS. The researchers were to conduct a review of mainstream and grey literature, create a bibliography of relevant literature, and develop a description of the CDS life cycle.

Annual Meetings

The Learning Network planned to conduct four annual meetings in Washington, DC, focused on topics relevant to improving dissemination of PCOR into CDS and patient-centered CDS (PCCDS).

Webinars

With input from team members, the SC, and AC, the Learning Network was to identify a set of topics and initiate an ongoing series of webinars during the first year.

Website and Resource Center

The Learning Network planned the development of a website to guide Learning Network members and the general public to project output and resources relevant to its mission.

Workgroups

Throughout the course of the project, as mandated by the SC, the Learning Network convened a variety of workgroups. After discussion and review in the SC, a series of workgroups were convened as shown in Exhibit 2.

Exhibit 2. Workgroups Convened

Workgroup	Charge
Barriers and Facilitators Work Group (BFWG)	The BFWG was to report on the state of PCOR evidence for self-monitoring blood pressure (SMBP) according to a matrix of barriers and facilitators based on the Analytic Framework for Action (AFA).
Trust Framework Work Group (TFWG)	The TFWG was chartered to propose a framework for promoting trust in shareable, modular, and publicly available knowledge artifacts for CDS.
Opioid Action Plan Work Group (OAPWG)	The OAPWG was charged with convening key stakeholders to identify ways to accelerate the creation, dissemination, and broad value generation from PCCDS for opioid prescribing and pain management.
Technical Framework Work Group (TechFWG)	The TechFWG was charged with addressing the technical barriers and facilitators to adopting shareable, modular PCCDS, and to developing recommendations for overcoming technical barriers to adopting PCCDS.
Patient-Facing App Work Group (PFWG)	The PFWG was charged with the development of a patient-facing prototype app for pain medication management and general application requirements for developing patient-facing apps.
The Sustainability Work Group (SWG)	Created to examine options for sustaining the activities of the Learning Network beyond the end of the cooperative agreement on January 31, 2020.

The Patient-Centered CDS eJournal

In the original proposal, the Learning Network committed to the creation of an eJournal as an outlet for peer-reviewed research supporting the dissemination of PCOR through CDS.

The Learning Network Self-Evaluation

The third specific aim was to monitor, evaluate, and adapt the Learning Network to optimally support the dissemination of PCOR findings into clinical workflows via CDS. The intent was to constantly monitor and improve the Learning Network and, additionally, to perform a more formal evaluation of the Learning Network's activities towards the end of the performance period.

Results

Findings and Outputs

Findings are organized by activity area.

Administration and Governance

The core team of staff at RTI International worked closely with a group of CDS thought leaders to manage the development of the Learning Network. A Steering Committee (SC) was formed to help provide input and guidance on a quarterly basis. For 2 years, the work of the SC was complemented by an Advisory Council (AC.) The two governance bodies (SC and AC) were composed of multiple stakeholder groups relevant to the dissemination of PCOR findings through CDS strategically advised and recommended actions for the Learning Network. In Year 3, the AC's role was determined to be redundant with the role of the SC and the decision was made to eliminate the AC and increase the number of members of the SC. Membership of the SC changed over the 4-year period; only a few members retained their roles.

The Environmental Scan

In its first year, the Learning Network conducted an environmental scan of the significant barriers and facilitators to the development and implementation of PCCDS (PCORCDS at the time). The [Environmental Scan](#) identified a number of significant barriers and facilitators that were reported to key personnel and the governance groups, resulting in initial recommendations for actions to improve the dissemination of PCOR findings through CDS. This work led to the development of a CDS [Analytic Framework for Action \(AFA\)](#) to describe the interrelated activities for transforming PCOR into use within learning health systems. The CDS AFA incorporates steps for disseminating, authoring, implementing, and measuring PCCDS to assess impact. Finally, the environmental scan recommended the creation of a barriers and facilitators working group to apply the CDS AFA to specific use cases to further ascertain challenges and simulate the key steps in turning a small set of PCOR findings into PCCDS, while carefully cataloging barriers and possible solutions at each stage. This information was used to generate further recommendations and actions. Additionally, conversations confirmed the need for additional working groups to address technical standards and pilot strategies that were also chartered.

Outputs:

- [Environmental Scan](#)⁷
- [PCCDS AFA](#)⁸

Work Groups

Barriers and Facilitators Work Group (BFWG)

The BFWG was chartered in October 2016 and concluded in December 2016. Its goal was to create one or more use cases describing the sequence of steps necessary to

1. Determine PCOR findings related to a specific clinical improvement imperative (e.g., hypertension control).
2. Identify barriers and facilitators to instantiating and widely implementing PCOR findings based on the AFA.
3. Recommend ways to overcome barriers and catalyze opportunities for PCOR-based CDS to promote improved care decisions, care processes, and actions.

4. Generalize results that elucidate for others the barriers, facilitators, and recommendations for PCOR-based CDS.

The group identified PCOR evidence for self-monitoring blood pressure (SMBP) as a single use case, developed a matrix of barriers and facilitators according to the AFA, and presented its findings at the 2016 Annual Conference (December 2016). Recommendations from the BFWG were to work with guideline developers and vendors to transform narrative guidelines into machine-readable guidelines, and to work with researchers and vendors to structure SMBP data in ways that could enable CDS triggers.

Trust Framework Work Group (TFWG)

The TFWG was chartered in January 2018 and concluded in September 2018. The TFWG brought together multiple stakeholders and proposed a framework for promoting trust in shareable, modular, and publicly available knowledge artifacts for CDS. Its work included the identification and characterization of nine trust attributes and 33 recommendations. The output from the TFWG was incorporated into the Opioid Action Plan released in January 2019. The TFWG material was disseminated via multiple channels, including a peer-reviewed manuscript, a conference presentation, and the AHRQ Care Transformation Support (ACTS) Roadmap. Members of the Mobilizing Computable Biomedical Knowledge (MCBK) Committee on Policy and Trust also received the TFWG material.

Outputs:

- [White paper](#)⁶
- [Journal article](#)⁹

Opioid Action Plan Work Group (OAPWG)

The OAPWG, which was chartered in March 2018 and met biweekly through December 2018, was charged with convening key stakeholders (payers, providers, CDS developers, EHR vendors, government agencies, patients, and others) and identifying ways to accelerate creation, dissemination, and broad value generation from PCCDS for opioid prescribing and pain management. The OAPWG developed an aspirational goal, five archetypical scenarios (use cases), recommendations for 19 high-impact CDS interventions, a commentary on implementation considerations, a listing of resources and activities, and a list of actions that stakeholders were taking to make the plan a reality. The Opioid Action Plan was published in March 2019. The OAPWG continued to meet on an as-needed basis throughout 2019 to maintain a collaborative forum for stakeholders to share information about their efforts for advancing PCCDS efforts aimed at opioid prescribing and pain management.

Outputs:

- [Opioid Action Plan](#)⁵

Technical Framework Work Group (TechFWG)

The TechFWG was chartered in January 2018 and concluded in September 2018. The TechFWG brought together multiple stakeholders and proposed a framework for promoting trust in shareable, modular, and publicly available knowledge artifacts for CDS. Its work included the identification and characterization of nine trust attributes and 33 recommendations. Its key deliverable was a white paper that was published in September 2018. This output was incorporated into the Opioid Action Plan that was released in 2019.

Outputs:

- [American Medical Informatics Association article](#)¹⁰

Patient-Facing App Work Group (PFWG)

The PFWG was chartered in March 2019 and concluded in October 2019. It was created to address two primary goals: (1) development of a set of patient-centered usability design guidelines for patient-facing CDS applications; and (2) development of recommendations for enabling interoperability of such applications with EHRs and their patient portals, as well as implementation of an initial prototype application to validate the feasibility of the recommended approach. Pain management was used as an example use case to focus

discussions. A total of 18 web conference calls were held biweekly between March 22, 2019, and October 25, 2019. All participants were asked to contribute both during and between meetings and to volunteer to present work of their own to the broader group on CDS-related initiatives. Patient advocates were actively engaged. Final report-out and vetting of the recommendations occurred during the Learning Network Annual Conference on October 21, 2019.

Outputs:

- AMIA Clinical Informatics Conference submission¹¹
- CDS Connect artifact
- Patient-facing CDS Infographic

Sustainability Work Group (SWG)

The SWG was chartered in April 2019 and concluded in January 2020. The SWG was composed of 14 experts in areas such as CDS, personal health, data and analytics, and devising funding strategies for start-ups. The SWG's goal was to promote safe and reliable patient-facing CDS through effective governance and standards by attaining sustainable funding to continue the Learning Network's business operations beyond January 31, 2020. The SWG members met monthly to review written materials and advise the project team on formatting and disseminating the materials. A subteam within the SWG conducted a high-level environmental scan to determine gaps and opportunities in the CDS ecosystem that could be addressed by the Learning Network.

In the Sustainability Proposal, we proposed establishing a Knowledge Network, based on the Learning Network's structures and its experiences, to focus efforts around standards development and governance of executable CDS. We believe a Knowledge Network can succeed based on the numerous examples of cooperative organizations that have established governance in support of sharing biomedical knowledge, such as the Sentinel Initiative, the Patient Innovation project, and the World Wide Web Consortium. The mission of the Knowledge Network would be to provide a pre-competitive platform to accelerate the translation of knowledge into practice. It would be a trusted entity to support collaboration and cooperation among stakeholders across the knowledge ecosystem.

Outputs:

- [The Sustainability Proposal](#)

Annual Meetings and Webinars

All annual meetings consisted of a full day of interaction with the community and thought leaders in the field. The meetings evolved over the course of the project to include presentations from experts in the field, including patients, researchers, and clinicians; interactive activities to help guide the work of the Learning Network; panel presentations to explore the state of the field from a variety of perspectives; and presentations from people working on innovative PCCDS in the field. In the final year, we provided the opportunity for researchers to present their work to the meeting. There were more submissions than we could accommodate with our schedule, which implies the need to provide a forum for researchers to share their work. Continuing to modify the meeting allowed us to keep the content fresh and embrace what was happening in the community.

The first meeting occurred in December of Year 1, and subsequent meetings were held in October of each year. Annual meeting summary data are in Exhibit 3. The project team worked to identify the themes and goals for each of the meetings and to identify candidates and topics for keynote speakers. Keynote speakers were identified to speak on topics aligned with the theme of each meeting. We reached out to potential speakers several months before the meetings to coordinate with them and ensure their presentations focused on issues that were key to our members.

Attendance at the annual meetings ranged from 80–100 people, which afforded participants the opportunity to make good connections, find other participants with shared interests, and continue their conversations after the meetings.

Each meeting was designed to achieve a different goal. We designed Year 1 such that it would set the agenda for the future efforts of the Learning Network. During the meeting, the attendees decided that

Exhibit 3. Annual Meeting Attendance and Milestones

Meeting and Theme	Dates	Participation	Key Events/Milestones
Annual Meeting 2016 <i>Conference and Strategic Planning Meeting</i>	December 12–13, 2016	Registrants = 51 <ul style="list-style-type: none"> ▪ SC/AC = 40 ▪ AHRQ = 2 ▪ Project Team = 10 	<ul style="list-style-type: none"> ▪ Changed project name from PCORCDS-LN to PCCDS-LN.
Annual Meeting 2017 <i>Realizing the Potential of Patient-Centered Clinical Decision Support</i>	October 3–4, 2017	Registrants = 74 <ul style="list-style-type: none"> ▪ SC = 10 ▪ AHRQ = 3 ▪ Community = 47 ▪ Project Team = 8 ▪ Speaker = 1 ▪ AC = 5 	<ul style="list-style-type: none"> ▪ Decided that next year’s focus would be on issues related to opioids.
Annual Meeting 2018 <i>Leveraging Patient-Centered Clinical Decision Support: Addressing the National Opioid Crisis and Beyond</i>	October 15–16, 2018	Registrants = 94 <ul style="list-style-type: none"> ▪ AHRQ = 4 ▪ Community = 71 ▪ Project Team = 7 ▪ Speaker = 2 ▪ SC = 10 	<ul style="list-style-type: none"> ▪ Determined that the focus for the upcoming year would be the technical challenges of PCCDS.
Annual Meeting 2019 <i>Optimizing Health Through Patient-Facing Clinical Decision Support</i>	October 21–22, 2019	Registrants = 71 <ul style="list-style-type: none"> ▪ AHRQ = 5 ▪ Community = 43 ▪ Panelist = 2 ▪ Presenter = 6 ▪ Project Team = 8 ▪ Speaker = 2 ▪ SC = 5 	<ul style="list-style-type: none"> ▪ Invited presenters from the community to show CDS efforts. ▪ Discussed options related to sustainability.

focusing on PCOR for CDS was insufficient for conveying the importance of patient goals, values, and preferences, and so the concept of “PCCDS” was introduced. After the meeting, in consultation with the SC, the Learning Network decided to focus more directly on the concept of PCCDS. Over the course of several months a definition for PCCDS was developed, and vetted with the SC, AC, and the broader Learning Network community.

Patient-Facing CDS

Patient-Facing CDS is CDS that supports care for specific patients, where a major role is played by one or more of these patient-centered factors:

- Knowledge: PCOR findings
- Data: Patient-generated health data; patient-reported outcomes and preferences; and patient-specific social, environmental, and cultural factors as they affect individual patient health
- Use: Patient (and/or caregiver) involvement in consuming and applying the decision support provided (e.g., information directed at patients/caregivers or for shared decision making)

In Year 2, we discussed the most-important issues facing the community and identified that in Year 3, the Learning Network should focus its efforts on the topic of opioids. During Year 3, we discussed progress from the opioid use case (OAPWG). This led to identifying a central goal in the final year of developing an application related to the opioid work. In Year 4, we highlighted work that was being conducted to advance patient-facing CDS.

Keynote Speakers

To maintain the reputation of the Learning Network and to encourage attendance at the annual meeting, it was important to have keynote speakers who would resonate with attendees. The RTI team identified potential keynote speakers to address topics consistent with each yearly theme through its contacts with experts in the field, reviewed current efforts in CDS, and reached out to potential speakers.

Year 2

- Dana Lewis spoke of her efforts to develop an artificial pancreas and of using open source technology to solve healthcare issues from a patient perspective.
- Dr. Ken Kawamoto spoke about technical and standards-based CDS.

Year 3

- Dr. David Bates presented on using technology to improve care, quality, cost effectiveness, and outcomes.
- Dr. Christopher Harle presented his work related to how IT-mediated communication tools affect consumer, patient, and provider decisions as they relate to opioid-based treatments.

Year 4

- Sarah Krüg spoke about the patient voice, how to ensure it is heard, and how to get patient input for decision support.
- Dr. Ted Melnick spoke on his efforts to integrate CDS into EHRs, including CDS that resonates with patients.

Webinars

The Learning Network scheduled webinars throughout the project; summary data are provided in Exhibit 4. Webinars offered the opportunity for presenters to provide information on their efforts to improve the Learning Network. The webinars were marketed through emails to our members and were posted to our website. Topics were identified by Learning Network staff, SC members, and other key thought leaders.

Exhibit 4. Webinar Registration and Attendance Rates

Title	Date	Registered	Attended
CDS for Pain Management	1/15/2020	289	144
Insights for Patient-Reported Outcomes in Cancer Care: New Opportunities in Patient-Centered CDS	11/2/2017	64	29
Insights for Scaling Patient-Centered CDS for Disseminating Guidelines in Public Health: A Case Example	9/14/2017	91	49
Insights for CDS Connect: A Patient-Centered CDS Authoring Tool and Rules Library	7/20/2017	201	115
Insights for Patient-Centered CDS Learning Network Open Forum	6/29/2017	123	58
Insights for an International PCORCDS Perspective: The Guideline Implementation with Decision Support (GUIDES) Project	2/16/2017	127	81
Insights for the Transformation of our Health System Disruptors and Implications for Clinical Decision Support	1/18/2017	153	84
Insights for PCOR Clinical Decision Support Interoperability Standards	12/21/2016	272	175

Highlights

- RTI hosted eight webinars over the course of the project.
- 926 people registered and attended these webinars, with 175 being the highest to attend a session.
- Most people (716) registered for or attended one webinar; however, others registered and attended multiple webinars.

The webinars allowed for a more in-depth conversation related to efforts to advance PCCDS. They provided a platform for a large number of diverse attendees to convene and learn from each other. As is typical with these efforts, more people registered than were able to attend, but by registering, they were able to access the materials after the webinars. This helped to promote PCCDS in a manner that was most convenient for the audience.

Online Collaboration: Website and Social Media Analytics

Despite a limited budget, we invested great effort into fostering collaboration with the use of electronic tools. This included the development of a public-facing website that originally incorporated some group support. For members of the project team and working groups, we added access to a secure Google Suite environment to support synchronous authoring and editing. Later, we added a Confluence space hosted by the Agency for Healthcare Research and Quality (AHRQ) to further enhance online collaboration. We developed other social media supports, including active Twitter and LinkedIn accounts. We present more details on these efforts in the sections that follow.

Learning Network Website Development

Year 1

Our objective in Year 1 was to build a web-based collaboration hub and content site to support the activities of the Learning Network, which we completed. In subsequent years, the website underwent enhancements and modifications.

Our completion of phase two of the website enabled improved functioning of governance bodies, distribution of content, archiving of key publications, and support for collaboration in forums and blogs.

Year 2

Based on discussions in Year 1, in Year 2 the Learning Network launched an [online Resource Center](#) with the goal of disseminating resources and ongoing initiatives in PCCDS. The Resource Center was a growing library of links within the following key categories:

- Evidence: Findings and evidence-based guidelines to enhance clinical care that could be implemented via PCCDS.
- Standards/Tools: Rules, methods, or utilities that could be used for structuring or delivering PCCDS interventions.
- Artifacts/Repositories: Patient-centered interventions, such as tools to gather, transmit, and provide feedback and guidance on patient-generated health data; and collections of such artifacts.
- Initiatives/Literature: Material describing development, implementation, or results from specific PCCDS interventions or approaches more broadly.

Year 3

The Resource Center incorporated the resources and actions of the OAPWG, and content related to the Opioid Action Plan. We created the Resource Center and continued to develop it until the end of the project. We also integrated the Confluence collaboration environment into the website. Lastly, we addressed specific areas as we transitioned to a focus on opioids. These included:

- How to grow the Resource Center, adapting it to the opioid focus
- How to efficiently add and manage site content
- How to better utilize the AFA
- How, and to what degree, to integrate Confluence
- Suggestions for new pages to add (e.g., CDS Connect, Opioid Center, Grant Pages)
- How to introduce a new feature/functionality
- How to address usability issues

In terms of overall engagement of the membership through the website, Google Analytics data indicate that over 15,000 users were supported over the 4-year period for about 22,575 sessions. This equated to about 55,500 pageviews with approximately 2.4 pages per session of about 2.3 minutes. Most of these visitors were using Chrome, IE, or Safari via a desktop system but a fair proportion (about 13%) were coming from a smartphone or tablet. Most-visited pages included the homepage, the conference pages, the AFA, and the Resource Center. More users were visiting for longer periods in the final year of the project.

Patient Expertise Blog

The Learning Network added the [Patient Expertise Blog](#), hosted by Danny van Leeuwen, an accomplished nurse, informatician, and patient advocate. Mr. van Leeuwen posted eight articles that address the intersection of patient experience and CDS from a patient perspective.

Miscellaneous Activities and Actions

In Year 3, we also added Confluence to our technical resources to enhance working group interactions. The TechFWG (Year 3) and the PFWG (Year 4) used Confluence to support collaboration and supplement manuscript development.

The Learning Network Self-Evaluation

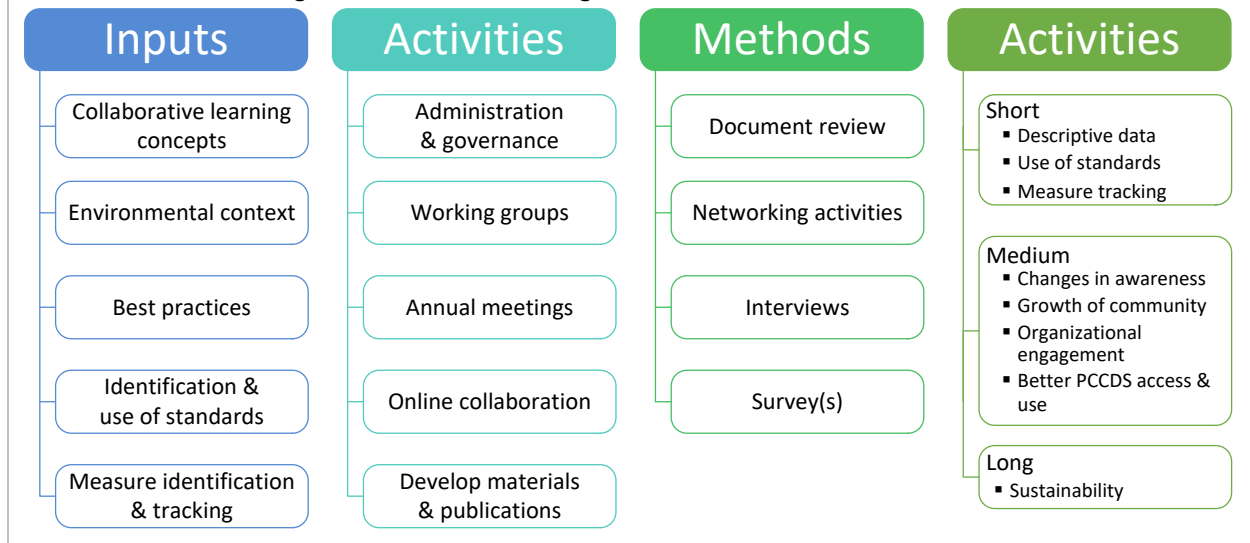
At its inception, the Learning Network was charged to monitor and measure its effect on the dissemination and use of PCOR findings in CDS tools and adapt its activities to increase effectiveness based on these findings. Throughout the first 3 years of operation, the Learning Network collected data on the impact of its interventions, and in Year 4 initiated a formal self-evaluation. The evaluation addressed questions such as:

- How has the Learning Network accelerated collaborative learning?
- Identified barriers and facilitators to implementing patient-centered and PCOR findings into clinical practice with the assistance of CDS?
- Fostered the implementation of PCCDS to address national healthcare improvement imperatives?
- Evaluated the Learning Network's impact and planned for long-term sustainability?
- Engaged stakeholders?

RTI used an evaluation framework based on Wenger's Theory of Change cycle for learning networks.¹² This included the examination of learning activities, members' engagement in activities, learning outputs, learning outcomes and impact, relationships between members, and measurable information about the impact the Learning Network had on the use of PCCDS in clinical practice. This work was guided by an evaluation logic model (Exhibit 5, next page) and organized around the core activities sustained by the Learning Network.

The results of the evaluation are referenced at numerous points in this final report. The full detail of the evaluation was submitted to AHRQ.

Exhibit 5. Evaluation Logic Model for the Learning Network



Development of Materials and Publications

The Learning Network produced many key publications including conference proceedings (n=4), peer-reviewed publications (n=4), white papers (n=5), and blog posts (n=11). In addition to this, in collaboration with AcademyHealth, the Learning Network developed a special section on PCCDS within Academy Health’s eJournal, eGEMs (Generating Evidence & Methods to improve patient outcomes).

eGEMs Journal Section: Better Decisions Together

The Learning Network launched an ongoing special section, titled “Better Decisions Together” in [eGEMs](#), an online open-access journal that featured peer-reviewed articles in decision support and electronic health data. The section disseminated compelling PCCDS findings, methods, and strategies to address the gap between research and use in patient care. The first call for papers went out in December 2017 and the first cohort of manuscripts was published in summer 2018:

- **Delivering Patient Data to Patients Themselves.** This introductory commentary by Dr. Ancker provides context around the section’s inaugural papers and emphasizes that we should not underestimate patients’ needs for information or their interest in learning.¹³
- **The Imperative for Patient-Centered Clinical Decision Support.** This article by members of the Learning Network outlined the AFA to organize thinking and activities around PCCDS. The article also discussed a wide array of activities the Learning Network is engaging in to inform and connect stakeholders.¹⁴
- **Methods for Patient-Centered Interface Design of Test Result Display in Online Portals.** This article reveals the importance of user-centered design in patient portals to help patients better interpret lab tests and make informed decisions. Researchers from the Veteran’s Administration hospitals in Houston and Salt Lake City, the University of Texas Health Science Center, University of Utah, and Baylor College of Medicine found that simply providing information is not enough, even when based on research about patient information needs.¹⁵
- **Generation and Implementation of a Patient-Centered and Patient-Facing Genomic Test Report in the EHR.** Researchers from Geisinger found that creating helpful patient-facing tools actually may require providing more information, not less.¹⁶

The journal section was not continued beyond the first call because of poor responses to calls for papers.

Discussion

Over the 4 years of the Learning Network's existence, we made significant inroads in both advocating for and improving the dissemination of PCOR through CDS, and in creating awareness of the importance of PCCDS. We also learned many lessons, some intrinsic to the project's management, governance, budget, skills, and focus, and others extrinsic, relating to the area of effort and nature of the tasks undertaken. The Learning Network would not have existed and could not have achieved results without the strong support of a volunteer army of stakeholders with a wide variety of roles and expertise. Our approach, using a large multistakeholder collaborative initiative, has many strengths that allowed us to achieve important results rapidly and at relatively low cost. However, volunteer initiatives such as ours also present certain challenges, and many of our lessons learned relate to the approach taken.

Given the limits of time and budget, there were many high import areas we were unable to address. We believe areas for a successor organizations to examine would be governance of executable knowledge (and PCCDS), knowledge management requirements for responsible stewardship and curation off PCCDS, and ways to create functioning marketplaces within a mixed public/private CDS ecosystem.

Patient-Centeredness

The Learning Network is, to our knowledge, one of the only organizations that has been strongly centered on and committed to the concept of PCCDS. It took the entirety of our first year of operation to realize the importance of PCCDS as a concept, and we at times vacillated in the degree to which we made PCCDS a core tenet of our mission. We believe that a greater focus on patient-centeredness was critical to advancing CDS, and any successor to the Learning Network should make patient-centeredness a key tenet of its mission from the start.

Lessons Learned

The Learning Network's SC, AC, and working groups all depended on the commitment and availability of highly skilled volunteers with expertise and records of leadership in all areas of the CDS ecosystem, characterized in the CDS AFA. Unfortunately, even with the best intentions, individuals were sometimes unable to participate consistently, and were occasionally unavailable at the times when their expertise was most needed. Over the course of the project, we learned how to better address this challenge; however, even with the best planning and management, it remained a significant obstacle to the project's success. Over time, we developed a set of best practices that improved the collaborative yield from our committees and workgroups:

- Always try to recruit a larger group than needed with redundant skills and expertise to ensure adequate attendance in meetings and support offline work between meetings.
- Be clear about the commitment expected and exclude participants that express reservations or caveats about their participation—their actual participation will invariably be low.
- Aim for working group participants who may working with the domain leaders but are a level down from those leaders themselves. These participants tend to be more available and more committed, while still having adequate domain knowledge.
- Promptly replace participants that miss too many meetings.
- Expect that a significant portion of initial working group meetings will be spent bringing participants up to speed on the problem to be addressed.
- Working groups should be led by a paid project team member with deep knowledge of the area of interest, and ideally paired with a volunteer participant with expertise in the same area.

The challenges for initiatives staffed by volunteers do not just include repeating discussions because of poor participation, slow progress, and insufficient or poorly informed output. There is also the danger (and often the case) that a small group of active participants might bias output toward one stakeholder group or underrepresent/underappreciate (or overrepresent) certain aspects of the problems to be solved. This can

lead to output that is lopsided in its coverage, or—at worst—output that is simply inadequate and not generalizable.

Other lessons learned that are specific to the way in which this particular project was conceived and executed:

- Labor was moderately underbudgeted for the work undertaken. The contribution of our external experts was extremely helpful and appreciated but was sometimes at the expense of core project staff hours.
- We generally underestimated the value and investment in upfront education required to support working groups and promote general learning within the CDS ecosystem. We believe that general learning through webinars and white papers should be a larger part of the mission for any successor to the Learning Network.
- Our experience developing and publishing *Better Decisions Together*, our joint eJournal development initiative with AcademyHealth, was challenging and ultimately unsuccessful. In the course of the effort, we realized that the creation and publication of a journal (whether paper or electronic) is a specialized domain that requires a specific skill set. We believe that the creation and dissemination of educational and research materials should be a core activity of an entity like the Learning Network, but in retrospect, we think existing channels for dissemination may be adequate. The creation and operation of *Better Decisions Together* diluted attention to the core multistakeholder collaborative mission of the Learning Network.

Limitations

The charge of the Learning Network was quite broad. We made substantial progress in numerous high import areas, but it is really just a start. In many cases, we were able to identify challenges and formulate recommendations, but could do little to enable them. There also were many important areas in which we could not engage at all, given the limitations of time and budget.

The project also had a very limited technology budget. Although we spent more effort than budgeted in the development, set-up, and maintenance of technology-based collaboration solutions, we did not fully reach our goals. Given a chance to reconfigure, we would allocate more-focused effort on this element of the work and ensure that any solution built could actually support the needs of the community.

Conclusion

The Learning Network was created as a multistakeholder collaborative to address barriers and facilitators to the dissemination of PCOR through CDS, formulate recommendations, and take action to improve the adoption and use of PCOR-based, PCCDS.

In 2016 and 2017, we worked to refine and focus the efforts of what was originally the PCOR CDS Learning Network into the updated goals of the Learning Network. This included identification of the components of the CDS ecosystem and the elements of the CDS life cycle, ultimately resulting in the publication of CDS AFA. Much of the effort during this period was spent on the PCOR to PCCDS dichotomy, resulting in the development of a better definition for PCCDS and adjustments to the Learning Network goals to reflect the PCCDS focus.

In 2018 and 2019 the Learning Network sharpened its focus on a specific key area: appropriate and inappropriate opioid use. This focus greatly facilitated our ability to demonstrate an impact on practice. The development of the Opioid Action Plan and the additional work on factors associated with development of PCCDS applications, including the creation of a patient-facing prototype app, all produced important results.

Future work in this area will focus on mechanisms to better support the use of computable biomedical knowledge within the CDS ecosystem. [The Sustainability Proposal](#) lays out a recommendation for a marketplace and environment, referred to as a “Knowledge Network,” to support a better functioning CDS ecosystem

Throughout the 4-year period, the Learning Network successfully identified key stakeholders in the CDS ecosystem and further developed a community to discuss, brainstorm, collaborate, and innovate on the concepts embodied by the PCOR CDS and the Learning Network.

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- Kensaku Kawamoto, MD, PhD, MHS, Associate Chief Medical Information Officer, Vice Chair for Clinical Informatics, Department of Biomedical Informatics, University of Utah
- Danny van Leeuwen, RN, MPH, Health Hats

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- Craig Umscheid, MD, MSCE
- Danny Van Leeuwen, RN, MPH, CPHQ
- Andrew Wiesenthal, MD, SM
- Kensaku Kawamoto, MD, PhD, MHS
- Robert Greenes, MD, PhD, FACMI
- Edwin Lomotan, MD, FAAP

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Appendix A. Publications/Presentations

White Papers

2020

- Richardson JE, Blumenfeld BH, Middleton B. A funding proposal for a sustainable knowledge network to support a more effective CDS ecosystem. Research Triangle Park, NC: RTI International; 2020 Jan p. 39. (Patient-Centered Clinical Decision Support Learning Network).¹⁷

2019

- Osheroff JA, Blumenfeld BH, Richardson JE, et al. A stakeholder-driven action plan for improving pain management, opioid use, and opioid use disorder treatment through patient-centered clinical decision support. Research Triangle Park, NC: Patient-Centered Clinical Decision Support Learning Network; March 28 2019. https://pccds-ln.org/sites/default/files/2019-03/LearningNetwork_OpioidActionPlan.pdf⁵

2018

- Middleton B, Platt J, Richardson JE, et al. Recommendations for building and maintaining trust in clinical decision support knowledge artifacts. Research Triangle Park, NC: Patient-Centered Clinical Decision Support Learning Network; September 21, 2018. https://pccds-ln.org/sites/default/files/2018-09/TFWG%20White%20Paper_final.pdf⁶

2017

- **Analytic Framework for Action:** Patient-Centered Clinical Decision Support Learning Network. Analytic framework for action. Rockville, MD: Agency for Healthcare Research and Quality; 2017. <https://pccds-ln.org/analytic-framework>. Accessed on January 27 2020.⁸

2016

- **Environmental Scan:** Patient-Centered Clinical Decision Support Learning Network. Environmental scan. Rockville, MD: Agency for Healthcare Research and Quality; 2017. <https://pccds-ln.org/environmental-scan>. Accessed on January 27 2020.⁷

Journal Articles

2019

- Richardson JE, Middleton B, Platt JE, et al. Building and maintaining trust in clinical decision support: Recommendations from the Patient-Centered CDS Learning Network. Learning Health Systems. 2019. doi: 10.1002/lrh2.10208.⁹

2018

- Marcial LH, Richardson JE, Lasater B, et al. The imperative for patient-centered clinical decision support. *EGEMS (Wash DC)*. 2018;6(1):12. doi: 10.5334/egems.259.¹⁴

Presentations

Anticipated 2020

- Marcial LH, Lasater B, Richardson JE, et al. Enabling Patient-Centered and Interoperable Patient-facing Clinical Decision Support: Recommendations from the Learning Network. AMIA Clinical Informatics Conference; 2020 May; Seattle, WA.¹¹

2019

- Marcial LH, Blumenfeld BH, Harle CA, et al. Barriers, Facilitators, and Potential Solutions to Advancing Interoperable Clinical Decision Support: Multi-Stakeholder Consensus Recommendations for the Opioid Use Case. AMIA Proceedings; in press 2019.¹⁰
- Blumenfeld BH. Results from a multi-stakeholder action plan to better leverage patient centered clinical decision support in addressing the opioid misuse crisis. AMIA 2019 Annual Symposium; 2019 November 16-20, 2019; Washington, DC.¹⁸
- Blumenfeld BH. New strategies for using patient-centered technology to improve pain management and opioid treatment. NM Health Extension Regional Office Seminar: Best Practices for Treating Chronic Non-Cancer Pain in Primary Care; 2019 July 9, 2019.¹⁹
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https://goto.webcasts.com/starthere.jsp?ei=1245838&tp_key=81dc05bc19. Accessed on June 19, 2019 2019.²⁰
- Blumenfeld BH. Addressing trust in clinical decision support knowledge artifacts. MCBK Trust and Policy Meeting; 2019 April 9.²¹

2018

- Richardson JE, Platt J, Blumenfeld BH, et al. Evaluating trust among multiple stakeholders for sharing knowledge in a clinical decision support ecosystem. 11th annual conference on the science of dissemination and implementation: scaling up effective health and healthcare: advancing the research agenda and necessary infrastructure; 2018 December 3-5; Washington, DC.²²
- Blumenfeld BH. Clinical informatics efforts to combat the opioid crisis—Experiences from the front line. AMIA clinical informatics conference; 2018 May 10; Scottsdale, AZ.²³
- Platt J, Richardson JE, Middleton B. Workshop: policy and coordination to ensure quality and trust in computable biomedical knowledge. 2018.²⁴

2017

- Blumenfeld BH. A learning network—Improving the dissemination of PCOR-based clinical decision support. Academy of Managed Care Pharmacy (AMCP). 2017 January 21.²⁵
- Richardson JE, Middleton B. Building nationwide capacity for PCOR-enabled CDS. RTI International Brown Bag Series (Online). Research Triangle Park, NC: RTI International; 2017.²⁶
- Blumenfeld BH. Accelerating evidence into practice: AHRQ's Patient-Centered Outcomes Research Clinical Decision Support Initiative. Washington, DC: National Academies of Medicine; 2017.²⁷
- Richardson JE, Middleton B. Building nationwide capacity for PCOR-enabled CDS. 2017 HIMSS Annual Conference & Exhibition; 2017 February 20; Orlando, FL.²⁸

2016

- Middleton B. Patient centered outcomes research clinical decision support learning network (PCOR CDS-LN). HL7 Advisory Meeting; 2016 July 18; Ann Arbor, MI. Health Level Seven International.²⁹
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- Blumenfeld BH. The Patient Centered Outcomes Research Clinical Decision Support Learning Network (PCOR CDS-LN): transforming patient centered research into action. AMIA 2016 Ignite Series; 2016 November 14; Chicago, IL. American Medical Informatics Association.³¹

Panel Presentations

2019

- Boxwala A, Desroche J, Middleton B, et al. Toward patient-facing clinical decision support: critical issues and near-term opportunities. AMIA 2019 Annual Symposium; 2019 November 20; Washington, DC.³²

2018

- Blumenfeld BH. Clinical informatics efforts to combat the opioid crisis—experiences from the front line. AMIA Clinical Informatics Conference; 2018 May 10; Scottsdale, AZ.²³
- Blumenfeld BH. Promoting trust in shareable CDS artifacts. AMIA 2018 Annual Symposium; 2018 May 10; San Francisco, CA. American Medical Informatics Association.³³

2017

- Callahan M. Analytic framework for action (AFA): A patient-centered outcomes research (PCOR) based clinical decision support (CDS) use case analysis. Health Datapalooza; 2017 April 27; Washington, DC. AcademyHealth.³⁴
- Richardson JE. The analytic framework for action: a novel framework for organizing efforts in patient-centered clinical decision support. Academy Health IT Interest Group; 2017 June 24; Washington, DC. AcademyHealth.³⁵
- Blumenfeld BH, Rutter JL, Siegel E, et al. Clinical decision support in the era of precision medicine. AMIA 2017 Annual Symposium; 2017 November 4-8; Washington, DC. American Medical Informatics Association.³⁶
- Lomotan EA, Bronkart DR, Blumenfeld BH, et al. Accelerating evidence into practice: AHRQ's clinical decision support initiative. AMIA 2017 Annual Symposium; 2017 November 4-8; Washington, DC. American Medical Informatics Association.³⁷

Posters

2019

- Richardson JE, Marcial LH, Middleton B, et al. Promoting trust, standards, and real-world applications for patient-centered clinical decision support. AMIA 2019 Annual Symposium 2019 November 18; Washington, DC. American Medical Informatics Association.³⁸

2017

- Marcial LH. Development of a proposed analytical framework for action for PCOR-based CDS: strengths and weaknesses. AMIA iHealth 2017 Clinical Informatics Conference; 2017 May 2; Philadelphia, PA. American Medical Informatics Association.³⁹

PCCDS-LN Webinars

2018

- Platt J. Trust frameworks: policy and legal issues in making patient-centered CDS truly shareable. Ann Arbor, MI: Division of Learning and Knowledge Systems, Department of Learning Health Sciences, at University of Michigan Medical School; 2018.
<https://primetime.bluejeans.com/a2m/events/playback/ded858ab-f1a6-4d75-9dab-2dd89d19143a>.⁴⁰
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Prevention, and Division of Disease Control—NYC Department of Health and Mental Hygiene; 2018. <https://pccds-ln.org/sites/default/files/2018-03/CDS%20for%20Immunizations%20%28CDSi%29%20A%20Community%20and%20Standards-based%20Approach.mp4>.⁴¹

2017

- Smith AW. Ask once, use many: new opportunities for patient-reported outcomes in healthcare delivery. *National Cancer Institute (NCI)*. 2017; <https://pccds-ln.org/sites/default/files/2018-03/Patient-Reported%20Outcomes%20in%20Cancer%20Care%20New%20Opportunities%20in%20Patient-Centered%20CDS.mp4>.⁴²
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- Blumenfeld BH. Introduction to the PCOR CDS-LN. *Patient-Centered Outcomes Research Clinical Decision Support Learning Network*. 2016; <https://attendee.gotowebinar.com/register/8884506229948816386>.⁴⁹

Conferences

- Fourth Annual Patient-Centered Clinical Decision Support Learning Network Conference; 2019 October 21; Washington, DC.
- Third Annual Patient-Centered Clinical Decision Support Learning Network Conference; 2018 October 15; Crystal City, VA.
- Second Annual Patient-Centered Clinical Decision Support Conference; 2017 October 3; Crystal City, VA.
- First Annual Patient-Centered Clinical Decision Support Conference; 2016 December 12; Washington, DC.

In the Press

2018

October 24th, 2018. Healthcare Informatics: Working Group Seeks Widespread Clinical Decision Support Implementation for Opioid Care by 2021. <https://www.hcinnovationgroup.com/population-health->

[management/patient-engagement/article/13030825/working-group-seeks-widespread-clinical-decision-support-implementation-for-opioid-care-by-2021](https://www.pccds.org/management/patient-engagement/article/13030825/working-group-seeks-widespread-clinical-decision-support-implementation-for-opioid-care-by-2021)

An Opioid Action Plan developed by a [working group](#) of the Patient-Centered Clinical Decision Support (PCCDS) Learning Network has set an ambitious goal of delivering PCCDS interventions that improve pain management and opioid use outcomes for 2 million patients by 2021. Provider organizations such as Kaiser Permanente and the Veterans Administration have already started using its framework to develop tools.

2017

October 4, 2017. POLITICO's Morning eHealth: *EPATIENTS V. PUBLIC HEALTH?*

<https://www.politico.com/tipsheets/morning-ehealth/2017/10/04/house-senate-panels-markup-chip-legislation-222639>

Scientists, vendors and patient advocates engaged in an intense discussion around patient engagement in the creation of clinical decision support at a conference outside D.C. on Tuesday. The AHRQ-funded Patient-Centered CDS Learning Network's goals are to create an infrastructure for sharing and developing CDS, including with patients. Allscripts' Leigh Burchell, who attended the network's annual meeting, said the idea was to get physicians to encourage their patients to use CDS—whether through apps on their phones or integrated into patient portals—and to feed data like blood pressure, glucose levels and weight gain back into their EHRs. Vendors' role is to create workflows for the patient data, she said, which is "pretty pie in the sky" but starting to happen.

Deloitte's Andrew Wiesenthal, a pediatric infectious disease doc and former Health IT Policy Committee member, said it would be "kidding ourselves" to think that most people would be engaged in managing their own diseases at such a detailed level. "The trick is not to get to the members of this society who will do things for themselves," he said. "The trick is to get to the hundreds of thousands who are not active, to give them tools to fit seamlessly into their lives."

October 3, 2017. How can patient-centered research plus consumer technologies improve health decisions? RTI International and AcademyHealth Partner on Open Access Journal to Advance Evidence on Patient-Centered Clinical Decision Support. <https://www.rti.org/news/how-can-patient-centered-research-plus-consumer-technologies-improve-health-decisions>

RESEARCH TRIANGLE PARK, NC— Electronic Clinical Decision Support (CDS) tools provide doctors with up-to-date evidence and information—often at the point of care delivery—to guide patient care. CDS tools can also deliver evidence from patient-centered research to patients, a goal of the Affordable Care Act.

RTI International and Academy Health today announced a partnership to launch a new, special section in Academy Health's open access, peer-reviewed on-line journal eGEMs. This special section will focus on patient-centered CDS.

October 3, 2017. RTI and AcademyHealth Partner to Advance Evidence on Patient-Centered Clinical Decision Support: eGEMs, AcademyHealth's open -access journal, will launch a new special section to help disseminate research findings. <http://www.academyhealth.org/blog/2017-10/rti-and-academyhealth-partner-advance-evidence-patient-centered-clinical-decision>

AcademyHealth is pleased to announce a new partnership with RTI International, a leading non-profit research institute, aimed at building the evidence base for patient-centered clinical decision support by launching a new special section in AcademyHealth's open access, peer-reviewed online journal eGEMs.

Journal

“Better Decisions Together” in eGEMs, an Ongoing Section on Patient-Centered CDS

The Patient-Centered CDS Learning Network launched an ongoing section, *Better Decisions Together* in [eGEMs](#), an online open-access journal that features peer-reviewed articles in decision support and electronic health data. The section disseminates compelling Patient-Centered CDS findings, methods, and strategies to address the gap between research and use in patient care. The first call for papers went out in December 2017 and the first cohort of manuscripts were published in summer 2018:

- **Delivering Patient Data to Patients Themselves.** This introductory commentary by Dr. Ancker provides context around the section’s inaugural papers and emphasizes that we should not underestimate patients’ needs for information or their interest in learning.¹³
- **The Imperative for Patient-Centered Clinical Decision Support.** This article by members of the Patient-Centered Clinical Decision Support Learning Network outlined the Analytic Framework for Action (AFA), to organize thinking and activities around patient-centered clinical decision support (PCCDS). The article also discussed a wide array of activities the Learning Network is engaging in to inform and connect stakeholders.¹⁴
- **Methods for Patient-Centered Interface Design of Test Result Display in Online Portals.** This article reveals the importance of user-centered design in patient portals to help patients better interpret lab tests and make informed decisions. Researchers from the VAs in Houston and Salt Lake City, the University of Texas Health Science Center, University of Utah, and Baylor College of Medicine found that simply providing information isn’t enough—even when based on research about patient information needs.¹⁵
- **Generation and Implementation of a Patient-Centered and Patient-Facing Genomic Test Report in the EHR.** Researchers from Geisinger found that creating helpful patient-facing tools actually may require providing more information, not less.¹⁶

In addition, several blog posts related to this section were created:

- [Opening Up Access to Research Findings.](#) In celebration of international Open Access Week, editor of eGEMs’ section Better Decisions Together, Jessica S. Ancker, highlighted progress in breaking down paywalls to make sure that research is available to everyone. POSTED Oct 24, 2018 BY [Jessica S. Ancker, MPH, PhD](#)
- [Leveraging Patient Insights to Improve Genetic Test Reports.](#) Interview with eGEMs author Jessica Goehringer about her new paper. POSTED Oct 4, 2018 BY [Jessica Goehringer](#)
- [Enhancing Online Portals Using Patient-Centered Interface Design.](#) Interview with eGEMs author Traber Giardina about her new paper. POSTED Sep 27, 2018 BY [Dr. Traber Giardina](#)
- [New Research Emphasizes Patients’ Role in Designing & Testing New Information Tools.](#) The first papers published in the ongoing section, Better Decisions Together, in AcademyHealth’s open access, peer-reviewed journal eGEMs highlight work to advance patient-centered clinical decision support. POSTED Jun 26, 2018 BY [Lauren Adams, M.A.](#)
- [Realizing the Full Potential of the Learning Health System.](#) The Health Care Systems Research Network is seeking submissions to include in a forthcoming special issue of eGEMs that will serve as an evidence-informed toolkit to address the complex attributes of health and health care. POSTED Jun 4, 2018 BY [Sarah Greene, M.P.H.](#)
- [Welcome to Better Decisions Together! A New Forum to Highlight Leading Research and Perspectives in Patient-Centered Clinical Decision Support.](#) New eGEMs section seeks to realize the dream of genuine patient-centered clinical decision support. POSTED Jan 12, 2018 BY [Jessica S. Ancker, MPH, PhD](#)
- [Jessica Ancker Named Editor of New eGEMs Section on Patient-Centered Clinical Decision Support.](#) An expert on facilitating good decisions through health information technology, Ancker has studied

both patient decision making and clinical decision support and brings valuable expertise to this new role. POSTED Jan 4, 2018 BY [Lauren Adams, M.A.](#)

Patient Expertise Blog

The Learning Network added the Patient Expertise Blog, hosted by Danny van Leeuwen, an accomplished nurse, informatician, and patient advocate. Mr. van Leeuwen has posted eight articles to date, which address the intersection of patient experience and clinical decision support from a patient perspective. Entries included:

- Decisions in a Bed of Trust, Part III
9/5/2018
- Decisions in a Bed of Trust, Part II
9/5/2018
- Decisions in a Bed of Trust, Part I
8/27/2018
- Measure Development: The Implementation
6/15/2018
- Measure Development: The Story
6/8/2018
- Innovating CMS Value-Based Measure Development
6/1/2018
- A Vision: Clinician and Patient Perspectives
5/22/2018
- A Vision: Inching Toward the Ideal
5/15/2018
- About This Blog
4/30/2018
- About This Blogger
4/15/2018
- <https://pccds-ln.org/patient-expertise-blog>.⁵⁰