

AHRQ CEDAR

Final Outreach Report

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Introduction

The Agency for Health Research and Quality (AHRQ) disseminates patient-centered outcomes research (PCOR) findings and other research evidence into clinical practice through clinical decision support (CDS). The AHRQ Center for Evidence and Practice Improvement (CEPI) maintains public repositories of research evidence and PCOR findings. Those repositories include [the Systematic Review Data Repository](#), [the Effective Health Care Program](#), [CDS Connect](#), and the [U.S. Preventive Services Task Force Recommendations](#). AHRQ recognizes a need for these repositories to be more findable, accessible, interoperable, and reusable (FAIR).¹

The CMS Alliance to Modernize Healthcare (the Health FFRDC), operated by The MITRE Corporation (MITRE), supports the CEPI Evidence Discovery And Retrieval (CEDAR) project in furtherance of the goal of making the CEPI repositories more FAIR. The project developed a standards-based application programming interface (API) that disseminates resources from multiple CEPI repositories through a single software-accessible endpoint, making the repositories (and the evidence they house) more FAIR.

Although much of CEDAR's first 2 years was devoted to technical development and testing, stakeholder input and feedback provided critical information to the project team. Discussion with end users of research evidence, repository stewards, and other stakeholders helped the MITRE team understand user needs, challenges, and experiences. This understanding contributed directly to technical development and supported the identification of CEDAR's first pilot partner.

This final report describes the ways in which the project team engaged stakeholders, how outreach findings were applied to project work, and lessons learned that can inform future CEDAR development.

The overarching goal of stakeholder outreach was to drive stakeholder interest, energy, and involvement during the development and establishment of CEDAR. Stakeholder engagement was intended to:

- Understand the landscape and usage of the AHRQ evidence indexed in CEDAR.
- Raise awareness of CEDAR and how it can speed finding and accessing evidence.
- Collect feedback to guide CEDAR development in accordance with end-user needs.
- Gather ideas about CEDAR's future growth.

Stakeholder engagement primarily consisted of information gathering, followed by application of those findings to development and pilot work. Because CEDAR indexes several CEPI repositories, stakeholders also shared input on those resources. MITRE applied this to CEDAR work and shared these findings with the respective repository stewards for their awareness. Stakeholder outreach

1 See, e.g., <https://www.force11.org/group/fairgroup/fairprinciples> and Wilkinson, M., Dumontier, M., Aalbersberg, I. *et al.* The FAIR Guiding Principles for scientific data management and stewardship. *Sci Data* 3, 160018 (2016). <https://doi.org/10.1038/sdata.2016.18>.

focused on landscape exploration, identification and implementation of strategies that would result in successful achievement of the goals, and ongoing evaluation and refinement of messaging and engagement. The Stakeholder Outreach Plan documented the scope and goals as a phased approach.

Stakeholder Outreach Plan and Activities

The Stakeholder Outreach Plan was developed at the beginning of the project and informed engagement throughout the 2-year project period. This plan broke the engagement work into four phases—Exploration, Strategy, Implementation, and Refinement—as detailed in the following sections.

Phase 1: Exploration

During Phase 1 exploration activities, the outreach team examined the current state of awareness and use of CEPI information, the type or category of CEDAR stakeholders, stakeholders' needs and expectations, and challenges to successful CEDAR implementation. The purpose of the exploration was to develop a common understanding among the MITRE and AHRQ teams of the purpose of CEDAR and the problem CEDAR solved, which would inform the future messaging strategy and broader engagement with the CEDAR end users. For purposes of CEDAR outreach and engagement, end users included those who will implement the CEDAR API into applications to access research evidence (e.g., software developers and platform designers). End users also included those who search for and use research evidence in their day-to-day work and processes (e.g., researchers, clinicians, and librarians).

This exploration was accomplished through a variety of activities, including conducting a general landscape survey as part of a larger environmental scan,² as well as holding interviews with CEPI repository stewards.

Individual discussions with the repository stewards enabled the MITRE team to identify people likely to use CEDAR, setting the stage for future stakeholder interviews. These discussions also helped inform the initial design of the reference implementation (RI).

MITRE's engagement with repository stewards also led to a better understanding of how changes or updates to repositories were currently communicated to the public, which helped MITRE plan for future communications regarding CEDAR. These stewards also described their communication with users of their repositories, unearthing and addressing their questions or problems. Appendix A contains the questions MITRE included in the discussions with the CEPI repository owners.

² FAIR Access to Patient-Centered Outcomes Research in AHRQ CEPI Repositories: An Environmental Scan to Inform the Development of CEDAR. (Prepared by Centers for Medicare & Medicaid Services Alliance to Modernize Healthcare (The Health FFRDC) under Contract No. 75FCMC18D0047.) AHRQ Publication No. 21-0032. Rockville, MD: Agency for Healthcare Research and Quality. May 2021.

The exploration phase of the Stakeholder Outreach Plan helped define a set of potential stakeholders and end users, such as “researcher” or “patient advocate.” This work underpins the eventual creation of pilot use cases, highlighting where and when CEPI information is most frequently used and for what purposes. This list of stakeholders and end users was further used to create a list of organization types that could serve as potential pilot partners.

Phase 2: Strategy

In Phase 2, MITRE and AHRQ collaborated to develop the stakeholder engagement strategy. The strategy identified outreach goals and a timeline for implementing the associated activities. Agreed-upon outreach goals were:

- Enhancing understanding of how the evidence indexed in CEDAR is used.
- Raising stakeholder awareness and understanding of CEDAR.
- Implementing CEDAR engagement and educational tools and materials.
- Improving understanding of stakeholder needs, perceptions, challenges, and expectations regarding the findability, accessibility, interoperability, and reusability of CEPI information to guide development and iteration of CEDAR.
- Strengthening existing and establishing new stakeholder relationships.

AHRQ engaged in the planning and development of the strategy direction, as well as in creation of the stakeholder engagement goals and plan. AHRQ also reviewed all outreach materials, providing input and approval prior to their dissemination.

Phase 3: Implementation

Phase 3, spanning much of the project’s 2-year span, involved implementation of stakeholder engagement activities. In this phase, MITRE obtained the necessary feedback from stakeholders on an ongoing basis, sharing the results with the CEDAR development team.

MITRE focused much of its effort in interviewing the end users of the CEPI repositories.³ MITRE invited nine end users of CEPI resources and programs to virtually discuss their experiences with CDS Connect, the Effective Health Care Program (EHC), USPSTF, the former National Guideline Clearinghouse (NGC),⁴ and SRDR. Questions focused on challenges and successes, information

³ The MITRE stakeholder outreach team completed a MITRE Institutional Review Board (IRB) “Request for Review of Human Subjects” form concerning the CEDAR stakeholder outreach and engagement interviews. The interview plan was also provided for review as evidence of compliance with all required IRB processes. MITRE’s IRB determined that the interviews were exempt from human subjects research and granted approval on June 23, 2021.

⁴ As part of the CEDAR project, MITRE assessed the National Guideline Clearinghouse (NGC) for its potential to be indexed into CEDAR if it is released again in the future. Although NGC is offline, it came up frequently in stakeholder discussions as a valued CEPI resource and so we have incorporated it into this final report to reflect stakeholder interest in it.

flow, and critical repository features. The interviews also introduced the end users to CEDAR; each end user was given an overview of CEDAR and a brief demonstration. Appendix B provides greater detail about the methods MITRE employed when conducting these interviews.

The interviewees regularly used at least one of the CEPI repositories discussed. MITRE’s analysis of interview data indicated several common themes among interviewees, including general agreement that AHRQ-provided research information is valuable and trustworthy. Interviewees also noted difficulties in finding AHRQ information, indicating a potential need to increase awareness of all the resources AHRQ offers. Interviewees unanimously supported the concept of a single point of entry to multiple AHRQ resources via CEDAR, suggesting that implementing CEDAR will increase efficiencies in reviewing and accessing CEPI information. MITRE recorded their suggestions for additional CEDAR functionality or development, and developers were able to take them into consideration.

From these suggestions, MITRE developed a set of short- and long-term recommendations related to CEDAR overall, though not all recommendations from end users were work that CEDAR could accomplish; some recommendations were more appropriate for either repository stewards or eventual implementers of CEDAR in external, third-party applications. These recommendations were captured, however, as part of the overall set of feedback provided by end users and through team discussion identified as either short-term or long-term recommendations. Short-term recommendations are those that could be implemented in CEDAR’s project period, while long-term recommendations are those that may not be able to be accomplished immediately but could be considered for future development (in 2 years or afterward). Table 1 contains a summarized list of these recommendations.

Table 1. Short- and Long-Term Recommendations Offered by CEPI Repository End Users

Recommendation	Short- or Long-Term
Ensure comprehensive search functionality, such as with the inclusion of additional search parameters.	Short-term
Incorporate AGREE (Appraisal of Guidelines for Research and Evaluation) ⁵ standards or other standards to sort or filter guideline artifacts.	Short-term; would also require repository steward participation
Favor speed and accuracy of results over robustness of content.	Short-term
Provide clear indicators of evidence timeliness and versioning.	Short-term

⁵ The Appraisal of Guidelines for Research & Evaluation (AGREE) Instrument (10) was developed to address the issue of variability in guideline quality. See, e.g., https://www.agreetrust.org/wp-content/uploads/2013/06/AGREE_II_Users_Manual_and_23-item_Instrument_ENGLISH.pdf

Recommendation	Short- or Long-Term
Incorporate additional AHRQ repositories or resources into CEDAR (example: Healthcare Cost and Utilization Project).	Short-term
Describe or detail contents of each repository indexed in CEDAR to provide immediate understanding of the scope of contents.	Short-term
Support and demonstrate the access of CEDAR information at the point of care.	Long-term
Enhance or further support different implementations of CEDAR in third-party applications (help vision the art of the possible).	Long-term
Enhance the design and curation of evidence within repositories that are indexed in CEDAR.	Long-term; would require repository steward participation.

MITRE has incorporated several of these recommendations into development of CEDAR. One such recommendation was to search by topic, keyword, and concept.

Other activities during the implementation phase included presentations, direct engagement with interested parties, and technical engagement, including how findings from those activities were incorporated into ongoing CEDAR development.

Phase 4: Refinement

Throughout the 2-year base period, MITRE engaged in a variety of opportunities to gather information pertinent to CEDAR development and to raise awareness of the CEDAR project. From each engagement, refinements were made to CEDAR’s messaging, and information was shared with the development and pilot efforts to support their work. During this phase, MITRE also drafted a communications plan to provide recommendations for ongoing engagement following the conclusion of the project.

Additional Outreach Opportunities

Direct Engagement

MITRE pursued a variety of additional opportunities to engage with subject matter experts (SMEs), as well as individuals or organizations engaged in similar or related endeavors to CEDAR. Goals of these engagements included initiating collaborative discussions, gaining an understanding of similar initiatives, and exploring potential future partnerships. SMEs and others were identified for engagement and discussion via recommendations from CEDAR stakeholder outreach interview participants, AHRQ CEPI repository stewards and staff, and MITRE SMEs familiar with AHRQ, PCOR, FHIR, API software development, and research evidence.

- **PCOR Expertise:** In February 2021, the MITRE outreach team engaged with a MITRE PCOR SME to explore the parameters and nomenclature of PCOR evidence, and to understand the scope of the data included in PCOR to inform FAIR assessments of the CEPI repositories and evidence. Based on this and related discussions with other FAIR and research experts, MITRE broadened the scope of its assessment tool so that it applies to evidence beyond PCOR topics.
- **Academic Institution and Public Health Expertise:** In September 2021, MITRE discussed CEDAR with Brown University School of Public Health’s Center for Evidence Synthesis in Health, Department of Health Services, Policy, and Practice. The discussion that followed provided valuable feedback on CEDAR’s development, which was consistent with feedback received from earlier outreach interviews with stakeholders and end users. MITRE also discussed CEDAR with researchers in several other public health programs at academic institutions.
- **Clinician Expertise:** Throughout fall 2021, MITRE engaged with different individuals representing a clinical end user perspective: a professor of family medicine and population health and participant in USPSTF, as well as representatives from several teaching hospitals to discuss potential use cases that would support the CEDAR pilot.
- **Developer and Technical Expertise:** In December 2021, MITRE and AHRQ engaged with other EBMonFHIR participants for an overview discussion. MITRE presented an overview of the CEDAR RI. MITRE subsequently participated in the EBMonFHIR track at the January 13-15, 2021, HL7 FHIR Connectathon and has remained engaged in the testing of resources relevant to CEDAR.

Presentations

The team presented on CEDAR at various meetings, “lunch & learn” events, and workgroups over the 2-year project period. The CEDAR team presented at a lunch & learn event at the University of Virginia Center for Advanced Medical Analytics, a session of the monthly CDS Connect Workgroup, and the Optum Interoperability Workgroup lunch & learn. These presentations were intended to share CEDAR’s objectives and technical design and demonstrate its functionalities.

Conferences

MITRE and AHRQ partnered to attend industry conferences as another means to promote CEDAR awareness. Many such conferences were open to a large and diverse range of audiences, therefore offering platforms to demonstrate CEDAR to and engage with a broader group that had little to no prior knowledge of the project. MITRE and AHRQ representatives attended two conferences in 2021 to highlight CEDAR. Attendance at other conferences, such as HIMSS, was curtailed due to the ongoing pandemic.

- Mobilizing Computable Biomedical Knowledge (MCBK) Annual Conference 2021 (July 20 – 21, 2021): AHRQ and MITRE representatives staffed a virtual technical poster session, offered demonstrations of CEDAR, and engaged in a question-and-answer session with conference attendees.⁶
- American Medical Informatics Association (AMIA) 2021 Annual Symposium (October 30 – November 3, 2021): AHRQ and MITRE representatives presented a poster that described the initial development work on the CEDAR API.⁷ The CEDAR project was honored with a Distinguished Poster Award.⁸

AHRQ and MITRE have had two proposed presentations accepted at the AMIA 2022 Annual Symposium, planned for November 5 – 9, 2022. During that event, AHRQ and MITRE representatives will offer a systems demonstration and a panel presentation. The systems demonstration will show how CEDAR optimizes the use of PCOR and research data by following standard guidelines for improving FAIRness in digital assets. The teams will also host a panel discussion offering perspectives on:

- Developing the CEDAR API.
- Collaborating with a clinical professional organization to deploy a client application using CEDAR to search for evidence.
- Designing, launching, and evaluating a CEDAR pilot activity.

Attendees will learn generalizable approaches to harmonizing metadata, using standards, and incorporating CEDAR output into guideline development and other products aimed at improving clinical decision-making.

HL7 Connectathons

HL7 Connectathons feature hands-on FHIR development and testing. Implementers and developers gain experience developing FHIR-based solutions by participating in one of many tracks the Connectathons offer. The CEDAR team participated in two Connectathons in 2021:

- At the January 2021 Connectathon, MITRE participated in the EBMonFHIR and FHIR4FAIR tracks.
- At the May 2021 Connectathon, MITRE participated in the EBMonFHIR track of the HL7 Connectathon to demonstrate data exchange using the Citation Resource.

Related to its HL7 Connectathon engagement, in January 2022, MITRE submitted a one-page proposal for a real-world scenario, *Center for Evidence and Practice Improvement (CEPI) Evidence*

6 MCBK conference materials are available at <https://mobilizecbk.med.umich.edu/news-events/annual-meetings/2021-meeting>

7 See, e.g., <https://amia.org/education-events/amia-2021-annual-symposium/program>.

8 Distinguished posters are selected from a slate of candidate posters recommended by the Annual Symposium Poster Committee and the Awards Committee during the poster sessions at the AMIA Annual Symposium.

Discovery and Retrieval (CEDAR) – Making evidence more FAIR, to the FHIR4FAIR FHIR Implementation Guide. CEDAR’s real-world use case has been accepted for inclusion in the guide in addition to several other similar real-world use cases.⁹

CEDAR and CDS Connect Showcase

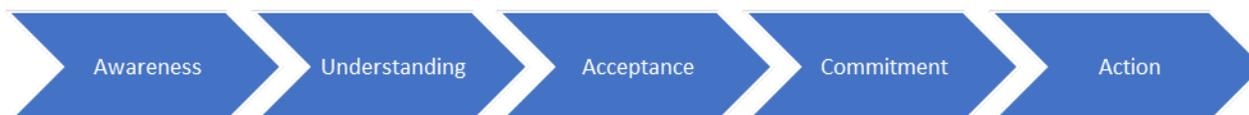
AHRQ and MITRE hosted an invitation-only virtual showcase on September 17, 2021, to highlight MITRE’s support of CEDAR and CDS Connect, two AHRQ PCOR efforts. A variety of stakeholders received invitations, including clinicians, healthcare systems, universities, professional societies, technology vendors, software developers, and medical librarians. AHRQ and MITRE demonstrated CEDAR’s use as a prototype software tool that improves the search and retrieval of PCOR evidence. Attendees also learned about available PCOR evidence released on the CDS Connect platform, which allows free access to promote the development and implementation of standards-based CDS. Finally, AHRQ and MITRE examined the CEDAR pilot planning effort, and illustrated their intention to engage with potential pilot partners.

Communications Plan

In Phase 4, MITRE developed a draft communications plan that documented suggestions and recommendations for AHRQ’s considerations when raising awareness of CEDAR and gathering information that can influence future CEDAR development. The plan is intended to be a living document that can support AHRQ beyond the end of the project period.

The communications plan is broken into five phases of impact on audiences and stakeholders, as depicted by Figure 1.

Figure 1. Communication Phases



- The first phase involves enhancing awareness about CEDAR by explaining its value and purpose to target audiences. During the awareness phase, communications focus on amplifying the compelling business reasons for using CEDAR. Team members evaluate any concerns of end users and other influencers and engage them to serve as advocates for using CEDAR.
- The second phase, which may be completed concurrently with the awareness phase, focuses on increasing the target audience’s understanding of CEDAR and its objectives. During the

⁹ See, e.g., <http://build.fhir.org/ig/HL7/fhir-for-fair/cedar.html>.

understanding phase, team members educate target audiences on how CEDAR benefits them and their work. Target audiences can provide input and feedback. They should be encouraged to ask questions.

- Once target audiences become aware of and understand how CEDAR can benefit them, the third phase involves obtaining acceptance. Trainings, demonstrations, walkthroughs, and other support can motivate target audiences to use CEDAR.
- The fourth phase is achieving commitment and is an effort tailored to the needs of identified audiences. Messaging should explain ways to take advantage of CEDAR in service of the audiences' specific systems and work. The commitment phase involves promoting and encouraging alignment and celebrating successes.
- The final phase is inspiring action by engaging with end users and other stakeholders already actively engaged with CEDAR. During the action phase, team members should capture and share lessons learned; refine expectations; and update communication activities, materials, and approaches based on feedback received from target audiences.

By continuing to regularly engage all CEDAR stakeholders, AHRQ can develop strong partnerships, answer questions, celebrate successes, address concerns, and improve interactions. Active use of a communications plan can support widespread awareness of CEDAR and robust stakeholder engagement.

Findings and Lessons Learned

Over the 2 years of the project, MITRE gathered input from a wide variety of evidence and repository end users, potential CEDAR users, and other interested parties. MITRE shared technical feedback, along with specific impressions of CEDAR's overall functionality, with the CEDAR developers; when appropriate, MITRE also used this information to inform pilot activities. Other data informed refinement to CEDAR messaging and plans for future work; it also helped shape related work in support of CEDAR (e.g., the development of the C-FAIR tool used by the team to measure the CEDAR API's alignment with FAIR principles).

MITRE's efforts captured the following findings that resonated across its engagement activities and that were shared with the development team, the pilot team, and AHRQ to consider for development, pilot, and socializing CEDAR purposes:

- Clinicians may benefit from access to a tool like CEDAR; having all relevant information accessible in one place will save time. In practice, CEDAR may be more useful before or after an encounter, rather than during a patient interaction. This is because the content that is indexed by the CEDAR API (guidelines, evidence reports, screening recommendations) and returned as search results in an application may be more useful when preparing for an encounter or for post-encounter followup and guidance than in the moment during an encounter.

- End users of CEPI resources have an expectation that CEDAR will index information from what are currently multiple silos and make the data available via a single access point, enabling end users to efficiently search and cross-reference information from all CEPI repositories.
- End users of AHRQ evidence express high confidence in the content of CEPI resources and programs, and they trust the information provided.
- End users such as researchers and clinicians are supportive of AHRQ's work to invest in CEDAR and see it as an opportunity for achieving better decision-making in their own work.
- Not all end users are familiar with all of the resources that CEDAR indexes, so the CEDAR owner should provide developer/designer end users with information about each of the repositories and the information that CEDAR indexes so that they can decide how to implement CEDAR to best meet their ultimate users' needs.

MITRE also documented lessons learned to reflect on the engagement practices used throughout the 2-year project period and for future application to CEDAR stakeholder engagement specifically. Lessons learned include the following.

- Sharing meeting notes and/or summaries with stakeholders provides transparency and clarity, and allows the stakeholders to add any missing details.
- End users valued, respected, and miss the NGC, and often raised NGC in discussion. When discussing CEPI PCOR evidence and evidence resources with any external audiences, preparation for questions about the status of NGC is essential.
- MITRE found value in ongoing coordination with CEPI staff during the engagement activities. This type of engagement should be a future guiding principle to ensure outreach and engagement success.
- When conducting interviews, it may be helpful to create an audio recording instead of relying on concurrent notetaking; interviewers would be free to concentrate on the exchange, thus reducing the potential for key information to be overlooked, forgotten, or missed.
- In engagements with any end user or other audience, it is critical to establish a baseline explanation of an API before proceeding with discussion of CEDAR, to ensure common understanding and vocabulary. This is especially true when providing a demonstration of CEDAR, as demonstrations rely on a user interface, and it can be easy for audience members to conflate the view of the user interface with the functionalities of CEDAR.

Conclusions and Recommendations

MITRE staff conducting the outreach described here found end users and stakeholders to be extremely involved and responsive throughout the various interactions. MITRE received valuable feedback and recommendations about the development of CEDAR and how it can deliver value to end users, whether developers/designers or researchers and other individuals who use research evidence. MITRE has incorporated several recommendations from the outreach interviews into the development of CEDAR; as a result, they are reflected in the version of CEDAR currently in use

with a pilot test. In addition, the CEDAR development team determined and prioritized recommendations that should be considered for future development.

MITRE recommends implementing a formal communications plan (as detailed earlier) to align with a key finding from the end-user interviews. For CEDAR to be successful, AHRQ should ensure comprehensive stakeholder awareness of CEDAR and other CEPI resources and programs. Although stakeholders overwhelmingly expressed the value of AHRQ evidence, they often shared the challenges they experienced in trying to find the specific information they sought. CEDAR can make it easier to find AHRQ evidence, and its comprehensive search results can add value to stakeholders by making end users aware of other resources and repositories maintained by AHRQ.

Appendix A. CEPI Repository Owner's Awareness and Understanding of Repository Users and Stakeholders

[Answers to this series of questions will help identify characteristics of individuals and groups who are likely to use CEDAR, which will be important for design considerations and for following up with actual users when feasible.]

How much do you know about the actual users of the (INSERT Repository name) repository (Individuals or Entities by name)?

How do you identify the users?

How would you describe the users (e.g., are they primarily clinicians, researchers, a mixture, etc.)?

Which users access the repository most frequently?

Would you be comfortable with us reaching out to several repository users to ask a series of questions about their experience and impression of the (INSERT Repository name) repository?

Which specific users do you recommend we reach out to?

Do you have contact information for them?

[Answers to this series of questions will allow the ability to target time and resources for CEDAR development more efficiently.]

Do you have information about the content and features that users find most important about (INSERT Repository name) repository?

Are users primarily focusing on certain aspects of (INSERT Repository Name) repository (e.g., accessing complete evidence reports)?

What aspects do users like about the repository?

What recurring issues, questions, or challenges do users raise about the repository?

In your view, what potential user-related risks or blockers could impact the CEDAR RI?

[These questions may help with better understanding the existing processes for communicating with repository users that might also be leveraged for future communication about CEDAR.]

How do you currently communicate with users?

How are you tracking user-identified issues?

Is there an analysis of user feedback—types of issues raised, cause/effect, related risks, etc.?

Is there a formal process for resolution of user-identified issues or challenges?

If yes, will you briefly explain it?

How do you communicate resolution of issues? (e.g., generate an FAQs document)

Additional user communication-related questions.

Do you synthesize user feedback about repository (INSERT Repository Name) and incorporate it into future workflows or improvements?

Have you identified any commonalities across repositories? Are you hearing the same comment about more than one repository from users?

Do you know if the repository owners share this information with each other?

Do you know how users hear about the (INSERT Repository Name) repository?

Is there anything you do to make new potential users aware that the repository exists? If yes, would you share some examples?

In your view, are additional outreach and education activities needed to raise awareness and understanding of the CEPI repositories?

Appendix B. Interviews with CEPI Repository End Users/Stakeholders

MITRE interviewed current end users of CEPI resources during CEDAR's 2-year project period. The goal was to understand what the end users knew about the resources indexed in CEDAR, their experiences with finding and accessing AHRQ information, and to share an early demonstration of CEDAR.

Interviews were conducted with a total of nine participants across a variety of end users. MITRE collaborated with repository stewards to develop an initial list of potential interviewees.

Repository stewards were asked to suggest specific individuals or organizations that were engaged with the stewardship of a repository or were known to be frequent users of CEPI resources and programs. Three out of six repository stewards provided a list of at least 10 potential interview candidates.

MITRE ensured the confidentiality of interviewee responses by further expanding the pool of potential end users to include MITRE SMEs and other contacts from early outreach activities. Ultimately, interviewees represented the following end user categories: clinicians, researchers, guideline developers, data contributors, librarians, specialty societies, universities, and healthcare systems.

An interview protocol was created and used during each interview. Interviewees were informed that MITRE was conducting the interviews on behalf of AHRQ and its work on a patient-centered outcomes research software development effort. AHRQ reviewed proposed interview questions in advance.

The interview questions were:

How would you define your role?

Which of the following do you or have you use(d) or visit(ed): the EHC website, SRDR/SRDR+, USPSTF, NGC, CDS Connect? How do you currently use the XX?

How do you start when looking for information? Can you walk us through your process? Workflow?

If you actively use XX, how often do you use it?

What do you believe is working well with XX? What do you believe is not working well?

Are there times when you cannot find what you are looking for or need to use another data source? If yes, what is it you cannot find? Where do you go to find it?

Do you ever need to find artifacts and other items such as clinical decision support tools, clinical guidelines, data underlying evidence reports that have been retired? How do you go about finding them?

What abilities or characteristics are most important for future development or changes?

What value do you get from the content you find in XX?

Do you have any general suggestions for improvements on how you find and access data housed in AHRQ repositories? Is there anything else you would like us to know?

What other evidence resources and programs outside of the EHC website, SRDR or SRDR+, USPSTF, NBC, and CDS Connect do you use? Why do you use XX?

Are there functions or elements of other evidence resources or programs that you find useful and think would be helpful if incorporated into this resource?

Do other evidence resources or programs you have used offer suggestions for related artifacts?

If yes: Have you ever read any of the suggested artifacts? Were they useful to you?

Would you like to see connections across evidence resources or programs?

If yes, what type of connections or relationships would you find helpful (e.g., similar title, similar keywords, visited by others looking at the current artifacts)?

Have you integrated any existing repositories into your IT systems (e.g., integrating a search function)?

If yes: Can you tell us how the integration works and what could make/have made it easier or better?

If no: Do you see any opportunities where integrating access to PCOR repositories directly into IT systems that you develop, manage, or use would benefit you or others?

Interviews were held virtually because of COVID-19 pandemic safety measures. Attendees from the MITRE outreach team included the interviewer, a note-taker, and a member of the CEDAR development team who provided a demonstration of CEDAR and answered questions related to CEDAR's technical specifications. Interviews were not recorded. Notes taken during the interviews were reviewed and coded according to a predeveloped taxonomy (see Appendix E). Responses were aggregated by question prior to delivery to AHRQ.

Coding began with an analysis of the exact responses, "source language" from interviewees, followed by a rating of the "measure of confidence" ranging from 1 (very low) to 5 (very high) in interviewee credibility and/or reliability to the various questions asked. All confidence ratings required a justification. In addition to a confidence rating, responses were also rated with a "measure of importance" ranging from 1 (very low) to 5 (very high) in interviewee position

and/or authority. All importance ratings also required a justification. The MITRE outreach team assessed each interview response for both confidence and importance.

Each coded interview response was analyzed for its content and then summarized as an observation. Over 100 observations were developed based on interviewee source language, confidence rating, and importance rating. After the series of interviews concluded, the multiple data points and interviewee inputs were categorized and analyzed to determine the overall themes and findings. Appendix F contains a table of all observations derived from the interviews.

Analysis of interview data indicates most interviewees share some common views regarding CEPI resources and programs. All interviewees regularly used at least one CEPI repository planned for indexing into CEDAR. Results of the qualitative analysis are detailed in the CEDAR Stakeholder Outreach Analysis Report. The results were provided to AHRQ in a separate report.

Appendix C. CEPI Repository End User Interview Taxonomy

This appendix details the taxonomy for the codes used to analyze the nine interviews with individuals representing nine stakeholder organizations. These interviews informed what was working well and what could have been done differently in how end users are using the repositories to inform the development of CEDAR.

Detailed notes were taken, which were then deidentified and entered into RIGOR, a MITRE tool for qualitative analysis. The taxonomy described in this document served as a codebook to code the nine sets of notes captured. The combined notes were provided to AHRQ for each individual question.

Repository Type

USPSTF: U.S. Preventive Services Task Force

EHC: Effective Health Care Program

NGC: National Guideline Clearinghouse

SRDR: Systematic Review Data Repository

CDS Connect: Clinical Decision Support

End-User Type

End users contacted for interviews were identified from the end-user types described in Table 2.

Table 2. CEPI End User Types Considered for Engagement

End-User Type	Examples
Care Delivery Organizations	Mayo Clinic, University of Pennsylvania Health System
Clinicians	Physicians, nurses, nurse practitioners
Medical/Clinical Associations	American Medical Association, American Academy of Family Physicians
Academic/Research	Johns Hopkins Research Triangle Institute-University of North Carolina
Patients/Caregivers	Patient Safety Action Network
Developers/Technology	Microsoft, Google
Health Standards Organization	HL7, SOLOR
EHR Vendor	Epic, Nextgen
Payers	CMS–Medicare, Medicaid, and the State Children’s Health Insurance Program (SCHIP), Kaiser Permanente

End-User Type	Examples
Quality Organizations	National Committee for Quality Assurance, National Association of Community Health Centers
Specialty Societies	American Medical Informatics Association
Federal Partners	Centers for Disease Control and Prevention, Office of the National Coordinator for Health Information Technology, National Institutes of Health
Policy makers – Federal, State, and Local	State/local boards of health, other Federal agencies
Healthcare Industry	Biotechnology, pharmaceuticals, and related life sciences (e.g., Pfizer, G.E. Healthcare)

Themes

MITRE developed a code dictionary of themes directly related to the questions asked during the interviews (see chart below). MITRE coded each set of notes using eight broad themes directly related to the questions to find commonalities across the different end users, choosing to keep these themes high level to better capture an overall view across all nine interviews. Table 3 shows the high-level themes with definitions.

Table 3. High-Level Interview Coding Themes

Theme	Definition
Positives	This describes what is working well or what would be beneficial. This can include current and future ideas. Examples: “I find it easy to search by keyword.” “I think it would be helpful if I could search by multiple terms.” Key words to tag: easy, helpful, like, good, works well, convenient, simple
Negatives	This describes comments related to areas that need improvement. What you want to see less. Examples: “The search function is hard to use.” “I can’t find the article I’m looking for.” Key words to tag: difficult, hard, dislike, poor(ly), could be improved, confusing, slow, time-consuming, challenging, obstacle, barrier, missing
Search Function	This describes items related to the search function. Examples: “The search function is hard to use.” “I can’t find the article I’m looking for.” Key words to tag: search, find, looking, keyword, full text

Theme	Definition
Artifact Availability	<p>This includes whether a person can find the guidelines they are looking for and if material has been removed.</p> <p>Examples:</p> <p>“I tried looking for a guideline, but the search has too many old versions.”</p> <p>“I know what I’m looking for, but I can’t find it where it should be.”</p> <p>Key words to tag: guideline, does not exist, error, link, up-to-date, update, broken links (webpage does not exist or cannot be found)</p>
Usage	<p>This includes how the repository is currently used and suggestions for future usage.</p> <p>Examples:</p> <p>“I currently use USPSTF to review the latest guidance on prevention.”</p> <p>“We use CDS Connect to inform tools we are building for EHR developers.”</p> <p>Key words to tag: use, search, review, up-to-date, current, leverage, incorporate</p>
Implementation	<p>This includes references to building technology tools or systems and/or activities interviewees have performed related to repositories.</p> <p>Examples:</p> <p>“We created an API using SMART on FHIR technology...”</p> <p>“We use HL7 to integrate PCOR data with an internal database in our EHR”</p> <p>Key words to tag: API, SMART, FHIR, implement, app, mobile, EHR, develop, build, create, share</p>
FAIR	<p>This includes any reference to FAIR guidelines (i.e., findable, accessible, interoperable, and reusable).</p> <p>Examples:</p> <p>“Our goal is to integrate PCOR into EHR databases so clinicians can find up to date information.”</p> <p>Key words to tag: find, findable, access, accessible, interoperable, reuse, reusable, across settings</p>
Future	<p>This includes references and recommendations for future development suggested by interviewees.</p> <p>Example:</p> <p>“It would be nice if we could integrate USPSTF into the research interface we use somewhere down the line.”</p> <p>Key words to tag: eventually, would like to, could, new, be of value</p>

Appendix D. Acronyms and Abbreviations

Term	Definition
AGREE	Appraisal of Guidelines for Research and Evaluation
AGS	American Geriatrics Society
AHRQ	Agency for Health Research and Quality
AMIA	American Medical Informatics Association
API	Application Programming Interface
CDC	Centers for Disease Control and Prevention
CDS	Clinical Decision Support
CEDAR	CEPI Evidence Discovery and Retrieval
CEPI	Center for Evidence and Practice Improvement (AHRQ)
ECRI	Emergency Care Research Institute
EHC	Effective Health Care Program
EPC	Evidence-based Practice Center
FAIR	Findable, Accessible, Interoperable, Reusable
GIN	Guidelines International Network
HHS	Department of Health and Human Services
IRB	Institutional Review Board
MCBK	Mobilizing Computable Biomedical Knowledge
NGC	National Guideline Clearinghouse
OBS	Observation in MITRE RIGOR Tool
PCOR	Patient-Centered Outcomes Research
PICO	Patient/Population, Intervention, Comparison, Outcomes
RI	Reference Implementation

Term	Definition
SME	subject matter expert
SRDR	Systematic Review Data Repository
UI	User Interface
USPSTF	U.S. Preventive Services Task Force