

**AHRQ**

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# CEDAR Option Period Outreach Report

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# Executive Summary

The Agency for Healthcare Quality and Research (AHRQ) Center for Evidence and Practice Improvement (CEPI) Evidence Discovery and Retrieval (CEDAR) application programming interface (API) disseminates findings from patient-centered outcomes research (PCOR), along with other types of research evidence, by making CEPI evidence more findable, accessible, interoperable, and reusable (FAIR). CEPI and MITRE executed outreach activities to obtain feedback from current and potential CEPI evidence users to guide CEDAR development. The project team also engaged with experts within the standards development community to ensure the API complied with current health interoperability and other standards, especially Health Level 7's (HL7's) Fast Healthcare Interoperability Resources (FHIR) specification. To test CEDAR, the project conducted two pilots and convened end-user focus groups for additional insights.

Between 2020 and 2023, the project team discovered several lessons about outreach engagement and communication methods, API use, and user preferences for accessing PCOR findings. This report describes the outreach, summarizes lessons learned, and delivers recommendations that can guide AHRQ's future decisions about CEDAR.

## Outcomes and Lessons Learned

- *AHRQ accomplished its primary objective to build CEDAR. The outreach and communications were focused on soliciting feedback to create a functional tool; future iterations will benefit from including outputs and outcomes measures to track outreach success in accomplishing program goals and objectives.*

The project must develop, implement, and track quantitative and qualitative measures to determine if and to what extent messaging reaches the right audiences, influences behavior, and results in actionable information to make decisions. Outreach communications that broadcast or deliver a standard, rote message to all groups are less effective in soliciting input and building commitment to an organization than an engagement and communication strategy of tailored messages and personalized contact designed to elicit feedback communication from specific individuals or groups. Moving forward, AHRQ should adopt measures to track how frequently outreach efforts connected with each group or individual, frequency of using each communications product, and similar "outputs" metrics. It should also track whether certain communications products and messages generated positive or negative responses from specific groups or individuals, whether outreach activities resulted in followup or additional meetings or engagement, and whether outreach to specific groups or individuals resulted in actionable feedback that AHRQ can apply to its programs. Taken together, these outputs metrics can be used to modify future outreach and

communications efforts as part of a process of continuous improvement to better assure intended results with each new communications and audience engagement cycle.

- *The project's outreach efforts informed successful production of the CEDAR API and identified a need for a widely available user interface (UI) without requiring new software applications to take advantage of CEDAR's capabilities.*

Successful outreach must reflect the project purpose; outreach efforts must rapidly change direction and tactics, as needed, to keep pace with new discoveries and lessons learned. Stakeholder feedback informed technical improvements to the CEDAR API functionality throughout the span of the project and revealed that the CEDAR Demonstration User Interface (CEDAR UI) was well received by users. The outreach over the last year expanded its scope to learn whether CEDAR would be adopted by its intended end users. Once CEPI further considers focus group feedback and other project insights, it may determine that additional refinements to the CEDAR API or to the CEDAR UI may be necessary and beneficial to optimize their use by the public.

- *To help plan CEDAR's next steps, it is essential to prioritize stakeholders based on impact and relevance to CEPI's goals. This can be determined by first, defining the problem statement that CEDAR is intended to answer, and second, selecting the audiences whose participation is critical to solve that problem statement. Once key audiences are identified, the communication strategy should be managed to provide the right information, at the right time, with the right context to ensure these community members are informed and can contribute recommendations or other feedback, while not becoming overwhelmed or disaffected by ongoing CEDAR engagement and messaging.*

Outreach is most effective when an organization first targets the critical audience(s) that can impact program outcomes, then balances the level of effort between managing stakeholder expectations and continuing to conduct engagement and messaging. Stakeholder management requires different outputs from communications management and is driven by an organization's desire to meet stakeholders' needs and concerns. When stakeholders are new to a tool and have limited context of its potential utility for their needs, then efforts geared toward the stakeholder and the relationship are necessary and communications likely will be more basic and informative. When stakeholders understand the tool's purpose, then efforts can focus on more specific information shared through communications and more individualized outreach activities. Each requires a solid understanding of how engagement will maintain good relationships with different stakeholders.

- *AHRQ should continue to refine its outreach to gain a clear understanding of how different audiences want to access and use AHRQ evidence and other resources. With this deeper understanding, AHRQ would be well positioned to make decisions about CEDAR and other methods to improve users' ability to leverage information in clinical decision making.*

Outreach targeted researchers, health information technology developers, clinicians, and others familiar with CEPI evidence; the team sought feedback from these audiences because it would provide immediate, actionable direction on how to establish necessary CEDAR functionalities. The project did not target patients or health plan representatives, as they were not seen as typical users of AHRQ evidence and would require different outreach approaches that were not feasible to complete within the project's timeframe. Recommendations from project outreach participants found that patients, clinical team educators, and patient advocates, for example, may welcome CEPI's outreach to learn more about CEDAR and how it could meet these audiences' information and shared decision-making needs. Recommendations from different participants in the Option Period outreach suggest AHRQ should consider patients, early-career researchers, and/or educational providers on clinical teams as likely CEDAR users.

- *Project outreach identified several individuals and organizations that have influential positions within the PCOR and API development communities who also hold AHRQ in high regard and trust its evidence. This esteem for AHRQ can establish a solid foundation for continued engagement efforts, so these individuals and groups should be recruited to form a foundational group of champions to advise on future outreach and messaging. They also can amplify AHRQ's reach by serving as influential outreach conduits.*

These champions share a commitment to AHRQ's success, along with a willingness to deliver objective feedback to help AHRQ retain and expand its trust with other stakeholders. Meaningful feedback received from many public groups and individuals throughout the project has already led to several enhancements to CEDAR's functionality. Closing the feedback loop through establishing the group of champions can identify opportunities for future growth. Their participation can inform CEPI's future revisions to the current configuration of the CEDAR API, promoting the greatest use by clinicians, researchers, developers, and knowledge managers. Moving forward, AHRQ should consider additional outreach to groups that are familiar with the information indexed by CEDAR, and initiate overtures to other groups not included in this project to understand their needs and interest in AHRQ evidence.

## **Recommendations**

CEPI should review this report's lessons learned and findings as part of its planning and scoping of CEDAR's next iteration, including decisions regarding pursuit of new tools or programs that fully meet users' needs. Success of CEPI's continued outreach efforts will require a defined problem statement that CEDAR is intended to address, as well as continued development and implementation of an outreach and engagement plan with performance measures. Fortunately, the healthcare community is receptive to efforts in modernizing healthcare and expanding access to information, which creates enthusiasm to participate in outreach and engagement. CEDAR can leverage AHRQ's trusted reputation to further engage target end users and determine the appropriate purpose and future directions of the tool. Ongoing outreach and engagement efforts are essential to confirm that AHRQ can disseminate PCOR findings to the broadest audience possible.

It is key for outreach efforts to continue communications with target CEDAR end users, including managing ongoing contact as AHRQ receives feedback and makes updates. Given CEDAR has only recently been made publicly available, it is insufficient to broadcast CEDAR's availability and features and to present to large audiences at industry conferences and events. AHRQ will need to specifically solicit, listen to, and act on user feedback and engage the full potential audience of PCOR users to assure CEPI's evidence retrieval program identifies and accomplishes its goals.

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## Introduction

The Agency for Healthcare Research and Quality (AHRQ) disseminates findings from patient-centered outcomes research (PCOR), along with other types of 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. Programs that support these repositories encompass the [Systematic Review Data Repository \(SRDR\)](#), the [Effective Health Care \(EHC\) Program](#), [Evidence-based Practice Centers \(EPC\) Reports](#), [CDS Connect](#), and [the U.S. Preventive Services Task Force \(USPSTF\)](#).

In 2020, AHRQ began work with the CMS Alliance to Modernize Healthcare (the Health FFRDC), operated by The MITRE Corporation (MITRE), to establish the CEPI Evidence Discovery And Retrieval (CEDAR) project to make the CEPI repositories more findable, accessible, interoperable, and reproducible (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) meet FAIR principles.

During the first 3 years of CEDAR development, piloting, and dissemination, feedback from the healthcare community was important to inform the future directions of CEDAR. This report describes the outreach strategies and activities the project team performed in assessing CEDAR.

All publicly available reports related to CEDAR can be found online at the same location on the [AHRQ Digital Healthcare Research](#) CEDAR Project page.

## Background

With the 2010 enactment of the Patient Protection and Affordable Care Act (ACA), Congress mandated that AHRQ disseminate PCOR findings into clinical practice. The law directed AHRQ to conduct two main actions:

- 1) [I]n consultation with relevant medical and clinical associations, ... assist users of health information technology focused on clinical decision support to promote the timely incorporation of research findings ... into clinical practices and to promote the ease of use of such incorporation.
- 2) [E]stablish a process to receive feedback from physicians, healthcare providers, patients, and vendors of health information technology focused on clinical decision support, appropriate professional associations, and Federal and private health plans about the value of the information disseminated and the assistance provided....<sup>1</sup>

Congress reauthorized the PCOR Trust Fund in 2019 as part of the Consolidated Appropriations Act.<sup>2</sup> AHRQ reinvigorated its efforts to disseminate PCOR findings and to engage with clinicians, researchers, PCOR evidence implementers, patients, and other stakeholders to help them gain timely and efficient access to AHRQ evidence that better informs healthcare decision making.

In 2020, in partnership with MITRE, AHRQ initiated the CEDAR project to provide enhanced search functionality of its CEPI repositories, as well as to promote access to their content in a manner that aligns to FAIR principles. A primary project task was to conduct outreach with the groups identified by Congress while developing the API. The work also included conducting an environmental scan and hosting pilots to test CEDAR.

## **Outreach Objectives**

AHRQ's outreach to promote CEDAR awareness and adoption set two project objectives: 1) inform development of the prototype API and 2) disseminate information to a wide spectrum of stakeholders about the AHRQ CEDAR project. The outreach scope centered on obtaining feedback to make the API more suitable for its intended audience. The project outreach was not intended to seek input from users on whether a different tool or process than API use would be more functional for them to access AHRQ materials.

To narrate the project's outreach work, spanning the contract's Base Period and the Option Period, this report:

- Summarizes the overall project outreach methods.
- Describes the Base Period approach.
- Describes the revised approach during the Option Period.
- Highlights key takeaways gleaned from stakeholder feedback and methods review.
- Proposes recommendations for future CEDAR outreach activities.

## **Base Period Approach**

As detailed in the 2022 Base Period AHRQ CEDAR Final Outreach Report published prior to the start of the Option Period, the project team developed and implemented a phased outreach strategy (including a recommendation for AHRQ to adopt a proposed communications plan) to improve stakeholder awareness of and commitment to using CEDAR. The Base Period outreach followed a broad informational awareness campaign: first, to alert users that CEDAR was under development, and second, to encourage them to provide feedback that would help ensure it met their needs. Both components sought to drive adoption interest and facilitate uptake of the CEDAR API. Base Period outreach initiated structured interviews with researchers and AHRQ repository stewards already familiar with the CEPI materials that CEDAR would index, as this knowledge could expedite preliminary API development functionalities. Environmental

assessments also showed that AHRQ resources typically are used by clinicians and guideline developers. Subsequently, the project team considered the insights of specific community members to be crucial in informing the CEDAR API development and prioritized outreach to representative user groups for feedback and pilot participation. Primarily, this was to begin outreach to audiences that immediately could benefit from using CEDAR in their work as an initial developmental exploration effort, and consequently did not include representatives from patient groups or from health plans. It was expected that patients or health plans may not use AHRQ evidence in a similar way or as frequently as other identified users. Additionally, many patients are unfamiliar with APIs and would be unlikely to offer recommendations on CEDAR's functionality. Establishing API functionality requirements for those groups would require outreach and communications that extended beyond the project's timeframe to ensure CEDAR operated in a useful way for audiences that do not regularly access AHRQ's resources.

## Stakeholder Outreach Plan

As described in the 2022 Base Period AHRQ CEDAR Final Outreach Report, the project team developed a stakeholder outreach strategy consisting of four phases:

1. *Exploration*: Examine stakeholders' current understanding, awareness, and use of CEPI information to define what problem CEDAR will solve and inform messaging strategy.
2. *Strategy*: Define outreach goals, establish implementation timeline, and create outreach materials.
3. *Implementation*: Obtain ongoing feedback from stakeholders and apply it to CEDAR development.
4. *Refinement*: Identify additional outreach opportunities and draft a communications plan to support future awareness campaigns.

The Base Period Final Outreach Report recommended a communications plan to guide future outreach activities to raise awareness of CEDAR and gather information to influence future CEDAR development. The plan described phases of impact on stakeholders and other audiences. While the plan discussed the activities to conduct during each phase, it did not describe how to elevate groups from one phase to the next. It also did not establish evaluation metrics (e.g., number of stakeholders to be reached via each type of communications or outreach engagement activity; number of times each stakeholder was approached) or outcomes measures (i.e., metrics to evaluate whether each engagement activity or communications method was successful in influencing the desired action of its intended target) to assess whether the communications plan, as implemented, was increasing interest in CEDAR and encouraging wider adoption. The plan recommended ongoing support for AHRQ's ability to engage all stakeholders to "develop strong partnerships, answer questions, celebrate successes, address concerns, and improve interactions."<sup>3</sup> While describing each phase was a necessary first step to illuminate opportunities for future AHRQ stakeholder engagements, the plan was incomplete in instructions to assess whether those opportunities were met.

As designed, Base Period outreach did contribute directly to CEDAR’s technical development. Feedback obtained through structured interviews with individuals already familiar with CEPI research presented specific insights into how these audiences use the evidence. This information also identified initial ways CEDAR could improve in both the API and the functionality of a demonstration user interface.

## **Conferences and Presentations**

The project team considered several conferences to determine where CEDAR presentations would reach attendees interested in its development and use. In the Base Period, the project team attended one conference to deliver a poster presentation, “Building With CEDAR and Making Evidence More FAIR,” describing the initial CEDAR API development work and AHRQ’s goals for CEDAR at the AMIA 2021 Annual Symposium.

The Base Period designed conference and presentation participation to deliver information broadly to a variety of targeted audiences. However, conducting outreach at the conference did not generate significant interest in CEDAR, as there were few follow-on conversations requested by potential end users after the conference.

While interactions with target end users was limited, this participation did generate interest and set the stage for the project team to initiate ongoing communication efforts. When it came time to identify a pilot partner, the project team reached out directly after the 2021 AMIA event with personalized, sustained contact with an American Academy of Family Physicians (AAFP) member with whom the team had engaged after the AMIA presentation. This continued outreach led to AAFP’s agreement to partner with the project team to test the CEDAR API. The group cited AHRQ’s reputation for producing high-quality research as an enticement, with the added benefit that working with AHRQ would support AAFP’s efforts to influence future PCOR development and findings dissemination on behalf of its members. This direct engagement, an outgrowth of the conference participation and specifically targeting an organization, demonstrated that impactful messaging can create enthusiasm for CEDAR’s capabilities. More importantly, it prompted AAFP’s possibility of creating a CEDAR application hosted on AAFP’s website for organization members to pilot.

## **Standards Development Organizations and Connectathons**

AHRQ directed the project team to host presentations and work with external collaborators, such as Health Level Seven (HL7), to leverage ongoing standards development activities. This work centered on the Fast Healthcare Interoperability Resources (FHIR) standard and the CEDAR project’s use of that standard. The purpose was to take advantage of HL7 processes and engage with standards experts so that CEDAR could rapidly integrate the appropriate parts of the FHIR standard and use implementation best practices. For example, connectathons—structured peer-to-peer testing environments for developing specifications and implementations—provide an important opportunity for the standards community to test products and share ideas. HL7 FHIR

connectathons offer hands-on testing of FHIR implementations; the team tested CEDAR in a FHIR Connectathon track during the Base Period, but not during the Option Period.

During the Base Period, the project team participated in the Evidence-Based Medicine (EBM) on FHIR track connectathons to ensure the CEDAR API implementation complied with FHIR standards. The FHIR citation resource implemented by CEDAR is not regularly tested within the EBM on FHIR track, reducing the value of continued engagement with the track's workgroup members. Instead, the project team leveraged CEDAR's Option Period Pilot activities to test interoperability and obtain standards compliance feedback. The team also participated in the FHIR for FAIR Connectathon track. This participation resulted in CEDAR's inclusion in the FHIR for FAIR implementation guide as a real-world use case.<sup>4</sup>

## Revised Approach for the Option Period

During the Option Period, MITRE reviewed the recommendations captured in the 2022 Base Period AHRQ CEDAR Outreach Final Report and the findings from the project's 2023 Environmental Scan. With this perspective, the outreach efforts shifted from creating a framework for *how* users could adopt CEDAR to one focused on obtaining pointed insights into *whether* CEDAR would be adopted. The team altered its approach to capitalize on the significant trust that AHRQ has earned with important user groups. This revised approach led to MITRE having direct individual and small-group conversations with professionals deeply involved in accessing CDS evidence through other interfaces. Experts engaged in this work appreciate the quality of AHRQ-generated evidence, yet they typically view it as only part of the relevant and necessary PCOR information they need to access. Building on experiences such as the Base Period's work with AAFP, the team decided that holding less formal conversations with experts would result in candid feedback about how useful CEDAR is in meeting their needs. Explicit feedback derived through these informal conversations would then help determine whether or not CEDAR had broad appeal—which would signal potential long-term viability for the API. It was important for the team to discover whether users wanted to see continued improvement in API functionality, or whether they questioned the need for this API.

## Engagement Strategy Changes

Most of the Option Period outreach was focused on conducting the Option Period Pilot. As a result, the team did not adopt the Base Period's recommended communications plan to drive widespread interest with all CEDAR stakeholders, and instead delivered specific messaging to each target audience to seek feedback on CEDAR. This approach was not explicitly designed to encourage target end users to adopt CEDAR, but to ask them whether CEDAR met their needs as designed or could be modified to be more useful. The project team identified specific thought leaders and subject matter experts (SMEs) to capture feedback on PCOR evidence use and API development and use to apply to CEDAR. While the team did not develop or implement measures to evaluate the strategy's effectiveness (e.g., quantitative metrics on improvement to

the CEDAR API and user interface), this insight provided timely feedback and helped to identify future actions. The reason why individuals who were invited to the informal conversations or the formal Pilot focus groups but did not participate was typically due to competing time commitments rather than a lack of interest in the CEDAR project.

## **Direct Discussions with Experts and Representative Users**

Because the CEDAR tool was in early development during the Base Period, outreach sought an understanding of CEDAR's eventual market environment. This initial feedback identified possible stakeholder adoption barriers, such as costs related to adoption or perceived lack of need for a new content search method, even as it was applied toward CEDAR functional enhancements. Leveraging this knowledge, the team adopted an outreach approach that emphasized sharing the centralized API search function within CEDAR with audiences to determine if its functionalities were sufficient for future users. The project team created a way for end users to search all CEPI content at once, directly on the AHRQ website, powered by the CEDAR API. This new CEDAR Demonstration User Interface (CEDAR UI) allowed users to perform searches and share input with the project team to refine the API.

## **Pilot Partnership**

A critical outreach goal involved identifying appropriate partner organizations to conduct project pilots and test whether CEDAR could serve needs of different users through one API. The team identified four categories, or types, of target CEDAR end users:

- *Clinicians*: Access information within their workflow for patient treatment and education.
- *Researchers*: Use, develop, and disseminate evidence to healthcare professionals, policy makers, and patients and clinicians for education and decision-making awareness.
- *Developer*: Facilitate technology adoption within an organization, including APIs like CEDAR, into client applications.
- *Knowledge managers*: Aggregate information from multiple evidence-based sources and databases into technical solutions that drive effective decisions.

Each of these target CEDAR end users provided insights about CEDAR's usefulness as an evidence-retrieval product. They also shared how they typically search for PCOR evidence and use it in their workflow, often in more detail or specificity than was obtained in the Base Period's structured interviews. This likely was because the outreach activities, especially the focus groups conducted prior to the Option Period Pilot, were designed to encourage free responses through general prompting questions, rather than the structured interview questions used in the Base Period. Additional information about the pilot and focus groups is discussed in the AHRQ CEDAR Option Period Pilot Final Report.

## Option Period Conferences and Standards Engagement

The project team considered presenting CEDAR at several conferences; AHRQ elected to launch CEDAR at the AMIA 2022 Annual Symposium, after productive engagement at the 2021 Annual Symposium with attendees. By delivering presentations and hosting an exhibit booth with companion communications materials, the project was able to re-engage AMIA Symposium attendees about CEDAR's development and showcase how CEDAR's functionalities achieved its initial goals. The Annual Symposium outreach was conducted in three parts:

- CEDAR: FAIR Clinical Evidence in Action (Session Number 37)
  - A systems demonstration that included an overview presentation and live demo.
- Need FAIR Evidence? Use CEDAR to Discover and Retrieve Research Findings (Session Number 04)
  - A panel presentation that provided an overview of CEDAR, reviewed the AAFP experience in creating and piloting a CEDAR API application on their website, and solicited feedback from attendees on future partnerships, applications, and directions.
- AHRQ CEDAR: A Direct Line to AHRQ-Sponsored Information and Evidence
  - An exhibit booth informational flyer to facilitate conversations between conference participants and AHRQ to generate further interest in CEDAR.

The project team also attended the 2023 AHRQ CDS Innovation Collaborative (CDSiC) Annual Meeting. Although this event was much smaller than each AMIA Annual Symposium, participation at the CDSiC meeting produced a marked change in the timeliness and quality of feedback that could inform CEDAR improvements. Coupled with its smaller conference structure, CDSiC's specialized participation resulted in the team's holding a larger number of immediate, personal interactions with attendees than previously during larger conferences.

The project team's primary role in attending the CDSiC Annual Meeting was to learn about new content being developed within the CDSiC workgroups that could be indexed by CEDAR. To prompt conversation with attendees, the team also staffed an informational booth and delivered a virtual demonstration of CEDAR's operation, using the CEDAR UI. Through this experience, the team identified prospects for future use cases and new key audiences, namely patients and patient advocates. It also signaled that hosting listening sessions, as opposed to presenting large-scale informational sessions, at conferences was a productive outreach method to achieve project objectives.

During the Option Period, the project team considered new engagement opportunities to take advantage of HL7 expertise. Rather than participate in connectathons to further refine the CEDAR API, the team proposed hosting a listening session during a scheduled connectathon to encourage participants to share emerging standards-based evidence retrieval methods that may be appropriate for AHRQ to explore in the future. Based on this proposal, AHRQ elected to host



a “Birds of a Feather” session at the HL7 Annual Meeting, FHIR Work Group Meeting and Connectathon held September 9–15, 2023, in Phoenix, Arizona. The session’s intent was to introduce participants to CEDAR’s purpose and invite conversations about what developers and knowledge management experts are currently working on (e.g., next-generation evidence retrieval or computable libraries). Through this approach, AHRQ could identify key individuals or organizations for future outreach and learn about projects that could spur future AHRQ actions to accelerate computable PCOR evidence use for CDS.

## Results

The outreach efforts unearthed several important improvements in methods used to elicit meaningful feedback and engage with stakeholders. These findings can help AHRQ determine whether to retain CEDAR, or instead pursue alternative ways for users to access CEPI evidence.

### Conducting Targeted Stakeholder Engagement

The Base Period used structured formal interviews and conducted conference presentations to encourage attendees to speak with the team in follow-on conversations. The Option Period approached specific PCOR SMEs and individuals familiar with API development explicitly to hold informal, candid conversations with these individuals and demonstrate CEDAR’s capabilities to elicit additional feedback. This shift to unscripted outreach helped the team more fully understand user needs, challenges, and experiences as they considered whether CEDAR provided an improved solution to other PCOR information search methods. It yielded specific feedback about CEDAR’s appeal that can shape CEDAR’s viability and value to expected user groups. The Base Period identified that target end users supported the concept of CEDAR, while outreach targets during the Option Period considered its relevance to their current work practices. The feedback was more pointed than that received during the Base Period, as target end users considered whether they would adopt CEDAR, not solely how CEDAR functionality could be improved.

### Determining Viability

Few outreach participants expressed interest in adopting the current version of CEDAR in their practice. Although they appreciated AHRQ’s commitment to make CEPI information more accessible, most respondents said they did not see an added benefit for using CEDAR as currently configured for clinicians, research experts, or knowledge managers. Overwhelmingly, target end users stated they prefer to conduct comprehensive searches for all relevant PCOR evidence; using CEDAR to find AHRQ evidence alone, disconnected from a wider spectrum of information, was not sufficient to meet their needs and change their search behavior.

Stakeholders repeatedly referenced two main criticisms or limitations when explaining their adoption reticence.

- Other products (e.g., PubMed, UpToDate) are more useful in meeting user needs for rapid, comprehensive access to evidence-based findings.
- The CEDAR-indexed materials within various CEPI repositories were neither sufficiently specific nor timely to inform decision making or guide researchers looking for reference sources.

Despite these limitations, the CEDAR UI saw consistent use, albeit from a small number of unique visits, during the Option Period. Over the Pilot period between July 2022 and July 2023, the CEDAR UI averaged 135 searches per day, with a total of approximately 12,400 searches overall during that period from 93 unique internet protocol (IP) addresses. Appendix B shows a log<sub>10</sub> graph depicting Option Period searches through the CEDAR UI over this timeframe.

Although the project envisioned users integrating the API into their own user interfaces, this did not occur during the project’s timeframe. The creation of a demonstration UI for anyone to use via the website was well received by many outreach respondents, and it generated recommendations and positive comments from individuals during the Option Period Pilot. One developer’s first impression of the Demonstration UI was that CEDAR is a “really cool implementation . . . very impressive.”

Stakeholders identified several significant opportunities for future CEDAR enhancement. Some recommendations focused on improving the API. Others suggested that future enhanced features for the CEDAR UI could make the CEDAR project relevant to more audiences:

- Because CEDAR indexes multiple source materials within AHRQ repositories, creating deeper tagging between those resources (i.e., connecting recommendations contained within artifacts, linking related content, clearly representing strength of evidence and quality of each recommendation) would be useful.
- CEDAR may become a method for researchers to discover research topics that AHRQ has yet to evaluate. In this way, the CEDAR UI could be used to identify and support initiatives that potentially enhance the CEPI portfolio and expand PCOR evidence over time.
- Addressing the limited quantity of artifacts CEDAR indexes could present an opportunity for AHRQ to partner with groups such as the National Science Foundation or agencies within the Department of Health and Human Services (HHS) so CEDAR can present more trusted and relevant information to users.
- CEDAR, whether through the API or CEDAR UI, could simplify an interface to segment indexed materials to the specific user group searching for information (e.g., guideline developer, general practice clinician, patient).
- CEDAR UI may provide a helpful resource for clinicians to use directly with patients, or to support clinicians as they seek to make differential diagnoses for patients. A future enhancement for the overall CEDAR project could include refinements in how the

repositories are indexed or organized. Focus group members recommended the following supporting ideas:

- Create a library based on patient characteristics and/or populations to support research, patient use, and clinical shared decision-making conversations.
- Build upon the USPSTF ratings system to create an objective scoring or “approval seal” to signal CEDAR-indexed content is trustworthy and unbiased.
- Organize CEDAR-indexed resources in a way that can promote “behavioral nudges” for patients based on trusted recommendations.

## **Outreach Lessons Learned**

The project team did not establish baselines of stakeholder awareness to assess changes in audience knowledge about CEDAR and identify whether or not outreach empirically led to increased likelihood of groups developing a UI to use the CEDAR API functionalities. Still, the outreach activities did accomplish their primary objectives of informing audiences currently engaged with CEPI about AHRQ’s intent to improve their access to AHRQ’s PCOR findings; this establishes a baseline for CEPI to continue outreach activities in the future. Lessons about outreach practices helped the team pivot from the original stakeholder plan after discovering that speaking directly to individuals or groups was more fruitful than general broadcast messaging through conferences and standards-development organizations. Adopting this direct outreach approach also served to identify a simplified, timely method to meet the engagement objectives and project goals.

The project also benefited overall from conducting outreach to a targeted set of potential API end users who have a general understanding of how APIs function, how PCOR findings should be presented for decision making, and an understanding of and need for CEPI evidence to conduct their work. While other audiences may benefit from improved access to AHRQ’s PCOR resources, additional outreach is necessary to confirm the need and identify a viable solution. The identified targeted end-user types, combined with feedback from outreach participants, afford CEPI an opportunity to confirm, refine, and possibly expand future stakeholder engagement audiences.

Additionally, the project team’s experience at the CDSiC Annual Meeting resulted in hosting a listening session at an HL7 Connectathon, rather than presenting CEDAR for additional Connectathon testing. These types of engagement with smaller groups proved useful in receiving timely, robust feedback that can support future CEDAR outreach planning and execution.

One improvement for future outreach would be to design measures to track how well the outreach efforts perform to support continuation or modification of the outreach plan’s activities. Generally, outreach metrics can be either quantitative outputs (i.e., counting the number and frequency of connections and what outreach method was used) or qualitative outcomes (i.e., tracking whether engagements led to attaining a particular project goal or objective). Examples

of qualitative metrics might include pilot partnership leads generated, specific technical recommendations made for the API, and interest in longer-term relationships or regular communications with AHRQ about CEDAR.

## **Redefining Key Audiences**

In part, the Base Period Pilot study established a series of use cases to indicate likely candidates for CEDAR adoption. To develop the Option Period Pilot study, the team revisited these use cases to select potential focus group members and pilot partners. (The AHRQ CEDAR Option Period Pilot Report provides greater detail about the use cases and how they apply to project work.) A close review of the updated use cases and focus group results yields candidates for AHRQ's continued outreach.

The project team connected individually with SMEs and professional colleagues aligning with target CEDAR user groups (typically those with interest in CEPI and other PCOR resources or with expert knowledge of API development for clinical use.) The team was able to synthesize an informal list of individuals who expressed interest in continuing their conversations and other engagement with CEPI about CEDAR. This key stakeholder group formed a target audience who trusted AHRQ's content and was interested in AHRQ's ability to improve the public's access to important resources.

Patients and patient advocates were not part of the project's stakeholder outreach strategy, but early CEDAR discussions and a visual infographic, describing how CEDAR works, included patients as a potential primary user.<sup>5</sup> An appropriate next step would be for AHRQ to explore whether and how patient audiences would be interested in improved access to CEPI evidence. Presentations and discussions during the 2023 CDSiC Annual Meeting demonstrated that AHRQ can empower individuals (whether self-directed or in collaboration with their clinical teams) to leverage PCOR evidence to understand their diagnoses or treatment options. Either through the CEDAR UI or through third-party applications, CEDAR could serve as a resource to which clinical team members refer patients who seek more detailed, evidence-based information about their care or their diagnosis. Furthermore, consumer health app developers may utilize the CEDAR API to include recommendations based on AHRQ evidence, creating a trusted source of information for clinicians to direct patients to for more information. In this way, AHRQ and CEDAR could improve shared decision making and individuals' self-care through evidence-based apps, while building trust in government-funded research with wider audiences.

Current CEDAR-indexed evidence is primarily aimed toward audiences with clinical and research expertise; these audiences are the primary groups who generate and apply the evidence funded by AHRQ research. Expanding its appeal to other individuals (including patients, caregivers, health plan providers, policymakers, and interested consumers) may require CEPI repository owners to work more directly with these groups to learn what changes are most relevant for them. A first step in developing consumer-centered evidence is to translate CEDAR-

indexed information (along with newly developed evidence from the CDSiC program) into plain language, perhaps storing these streamlined artifacts in a separate patient-focused CEPI library. This step would make the content easier to understand for individuals not trained in clinical or research protocols and encourage app developers to integrate it into consumer apps and shared decision-making resources that prioritize consumer understanding.

Additionally, AHRQ should engage directly with patients and others to learn what evidence they find most useful, then use those insights to inform other AHRQ programs; for example, AHRQ can update its grant opportunities to fund the generation of evidence that meets the interests and information needs of patients and their caregivers and make grant awards predicated on how evidence will be tailored to different audiences. To accomplish this, AHRQ may choose to model its patient-engagement efforts for CEDAR development on the Food and Drug Administration's Patient Engagement Advisory Committee to include the patient perspective in the grant review and approval process.<sup>6</sup>

By reviewing project use cases, assessing results from the Option Period Pilot, gathering feedback from user focus groups, and synthesizing other stakeholder information, CEPI can revise its pool of key audiences and develop a stakeholder management strategy to support and guide future outreach. As the CEPI team builds additional experience conducting streamlined outreach and tailored messaging, it can consider expanding its outreach strategy to target additional audiences that currently may be less engaged or require extensive education to understand how to use CDS resources. At that time, CEPI may decide to undertake new engagement activities or establish new use cases and audiences for CEDAR to reach the full array of audiences initially described by Congress when the PCOR Trust Fund was established.

A gradual expansion of its audience permits CEPI to:

- Assess stakeholder feedback when determining whether to retain and revise the CEDAR API.
- Consider whether there are significant gaps in existing AHRQ evidence that would meet new or existing users' needs, or whether existing evidence should be presented in new ways to appeal to various audiences.
- Unearth and incorporate emerging technologies or methods to improve access to and timeliness of PCOR evidence for all interested groups.

## **Leveraging AHRQ's Reputation as a Trusted Entity**

Engaging regularly with interested audiences—and bringing new audiences into the AHRQ outreach planning—enhances AHRQ's current institutional credibility as a source of high-quality evidence. Stakeholders demonstrated their trust in AHRQ and its evidence; from the project outset, they held AHRQ in high regard for its impartiality in evidence generation, as well as for improving healthcare quality. By contrast, stakeholders expressed their view that pharmaceutical

and device companies, professional organizations, and health plans have a greater vested interest in evidence generation and what CDS tools are promoted to users. Even when individuals had little experience with APIs, the fact that AHRQ was developing such a tool enticed those stakeholders to learn more about AHRQ's goals for CEDAR. They also expressed an openness to consider whether or not it would provide value to their professional work.

This level of institutional regard is significant; several notable publications and surveys find that the public has limited trust in government overall and in information it releases to the public. For example, Edelman (a company that conducts research to educate leaders and inform their leaders' institutional strategy, policy, and action)<sup>7</sup> released a special report on trust and health in April 2023,<sup>8</sup> which states:

44 percent of respondents aged 18 – 34 said that an average person who has done their own research is as knowledgeable on most health matters as doctors. ... Consider those who both believe that the average person can know as much as a doctor and that the system is failing: nearly half say that they have followed peer or social media advice that contradicted their own doctor in the past year. ... We need to [give] them the chance to ask questions, to absorb the science gradually. ... It is our responsibility to educate and empower them.<sup>9</sup>

Similarly, the Commonwealth Fund (an organization that supports independent research and healthcare practice and policy) recently convened a commission to study potential recommendations on the Nation's public health system. It reported that trust in public health would require significant changes in communication when sharing information.<sup>10</sup> A *Health Affairs* Forefront article addressing this report stated:

[t]he proliferation of health misinformation and disinformation has decreased the public's acceptance and effectiveness of these public health communication strategies and has adversely impacted trust between the public and government. Now more than ever, we must communicate using methods that will reach and resonate with the public while actively rebuffing disinformation. ... Concerns regarding how health data will be interpreted by the public, and the risk of health data being used out of context to create disinformation, are less important than the need to provide accurate, understandable information to the public for action. Transparency can increase the public's trust in governmental public health systems and diminishes the perception that governmental public health organizations are "hiding the truth."<sup>11</sup>

AHRQ can build upon the trust held by clinicians and researchers by updating how evidence is displayed and expand CEDAR's viability. Making CEDAR content more consumer-approachable and -readable would give clinician teams additional resources in shared decision-making conversations with their patients and others. Clinicians who refer their patients to these resources could earn patient respect as trustworthy partners whose decisions are informed by impartial evidence, instead of using branded marketing sites or products. Over time, consumers may become more confident in government's role in shared decision making and encourage its use within the healthcare system. CEDAR-indexed evidence could become a primary resource accessed in clinician settings to educate patients about their healthcare options, as well as power consumer apps that patients and consumers seek out independently.

During focus group conversations, clinicians and researchers alike suggested that AHRQ maximize users' belief that its research is trustworthy. Some commenters inquired whether AHRQ could implement a "seal of approval" on indexed evidence to signal its objectivity, and/or find a way to make evidence more findable for patients searching for information about their diagnosis.

Patient advocacy organizations already are encouraging researchers to consider a more equitable approach to evidence generation and dissemination to drive more effective shared decision making. One nonprofit, the National Partnership for Women and Families, advocates for leveraging 21st-century technology to give families and providers information that supports care coordination and informed decision making in private, secure, and accessible ways. Its report, "Patient and Family Engagement: Improving Health and Advancing Equity,"<sup>12</sup> analyzed findings from research funded by the Patient Centered Outcomes Research Institute. The report recommended that researchers and clinical care providers focus on trust and improved patient education as methods to engage patients and families in effective shared decision making.<sup>13</sup>

Overall, AHRQ's mission and the goals of PCOR align directly with this degree of public trust. Expanding CEPI outreach beyond the work conducted in this project contributes to AHRQ's Strategic Framework for the Patient-Centered Outcomes Research Trust Fund (PCORTF),<sup>14</sup> especially two themes expressed in a recent AHRQ blog post:

Formal processes are needed to ensure **stakeholder engagement** throughout the research process. Research findings must be provided to communities in assessable and actionable formats for sharing with the public, policymakers, healthcare executives, clinical leaders, and others. ... Erosions in **trust** must be recognized and addressed. Trust among patients and providers must be prioritized and extended to co-creating new and meaningful ways to achieve whole-person care.<sup>15</sup>

The following findings support a more expansive role for CEDAR, CEPI, and AHRQ.

- AHRQ’s reputation as a trusted entity is the most important asset for CEDAR’s adoption.
- The experience of instituting CEDAR provides important lessons that inform overall Agency strategies to meet priority goals. CEPI represents one contributor to successful AHRQ priority and cross-cutting goal accomplishment.
- CEPI and AHRQ can continue and expand internal HHS partnerships to identify new opportunities to distribute PCOR findings and align strategies to implement PCORTF goals and objectives. These partnerships can streamline integration of additional evidence through CEDAR, while broadening its availability to more audiences.
- Additional partnerships with other organizations, such as the Patient Centered Outcomes Research Institute (PCORI) and with advocacy groups, could also identify new pathways for CEPI evidence dissemination.
- If CEDAR is to be adopted by a variety of users, then CEPI needs to invest in a broader outreach effort to explore how CEDAR can index additional resources that meet the needs of prioritized users already familiar with AHRQ evidence.
- The CEDAR UI offers a simple, easily accessible resource that any audience can use with minimal training or experience. This opens new opportunities for CEPI to engage with audiences looking for information to support their healthcare decisions.
- AHRQ may investigate opportunities to integrate CEDAR into its research funding announcements and processes, so that applicants would use CEDAR to identify evidence gaps. CEPI could advise grantees to review existing CEDAR repositories and indexed information to identify possible gaps or improvements. For example, applicants could be asked to include descriptions in their grant proposals of how their findings should be tagged and indexed so that it will meet CEDAR’s FAIR principles. Opportunity also exists for applicants to describe which audiences should be able to access their findings if the grant is awarded.

## **Establishing AHRQ Stakeholder Champions**

Individuals who participated in the Option Period Pilot focus groups (representative of key user groups and CEDAR use cases) could serve as the foundation of a CEPI-specific champions group. In addition to expressing their trust in AHRQ evidence quality, these individuals also spoke of their deep respect for AHRQ’s intent to introduce a tool that supports improved evidence accessibility to broaden the public’s use of PCOR findings and resources. They advocated for AHRQ to continue building these resources and improving the repositories overall. By nurturing these existing relationships, CEPI can stimulate cooperative information sharing as the centerpiece of an ongoing stakeholder outreach and management plan for CEDAR and future demonstrations. A strong outreach strategy founded on these champions could identify new ways to show patient groups, consumer advocates, and policymakers, among others, that AHRQ evidence presented through CEDAR is a valid source of health information for clinical and individual health decision making.



## Recommendations

The following recommendations capitalize on the findings and insights distilled from the full timeline of project outreach, highlighting options that CEPI will need to evaluate in context of broader AHRQ goals (e.g., AHRQ Patient-Centered Outcomes Research Strategic Framework, contributions to the HHS Strategic Plan, PCORTF strategic implementation) to determine the appropriate path forward for CEDAR.

### Explore Opportunities for Future Outreach

CEDAR signals AHRQ's intent to adapt to the changing needs of current and future users in accessing PCOR in a timely and efficient manner. Potential users generally were open to learning about the CEDAR prototype and its purpose, even when they were skeptical about whether the API could directly benefit them. Stakeholders expressed a desire for more AHRQ evidence, as well as improvements so users can find information specifically relevant to them.

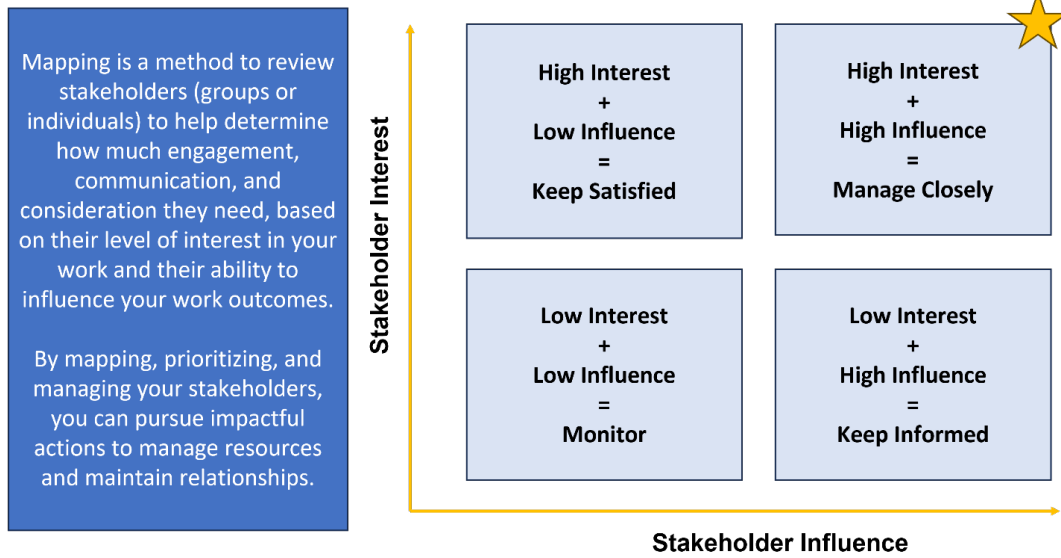
CEPI should determine communications frequency with each targeted user group, based on their ability to influence program decisions. Preliminary planning involves conducting a mapping exercise to confirm or challenge AHRQ assumptions about its evidence use, allowing CEPI to manage its resources and maximize engagement impact by tracking and addressing changes in stakeholder needs and interests. It does not differentiate between "external" or "internal" groups; stakeholder identification would be the first step of the mapping and planning process.

A stakeholder mapping matrix positions groups within a four-quadrant grid. The Y-axis shows their level of interest in an organization's policies or programs, and the X-axis shows their level of influence on an organization's success. Groups mapping to the upper-right quadrant (high interest, high influence) would warrant the highest engagement level; those in the lower-left quadrant (low interest, low influence) could be kept informed through less-intensive efforts, monitored periodically to confirm that messages resonate and drive action as anticipated. Stakeholders in the other quadrants would require intermittent management but would be expected to contribute insights over time as their interests evolve or change.

Figure 1 is a mapping-matrix diagram that informs choices about levels of engagement with selected stakeholders for information-sharing and feedback activities, balanced by expectations based on whether their involvement will impact program and policy decisions and outcomes.

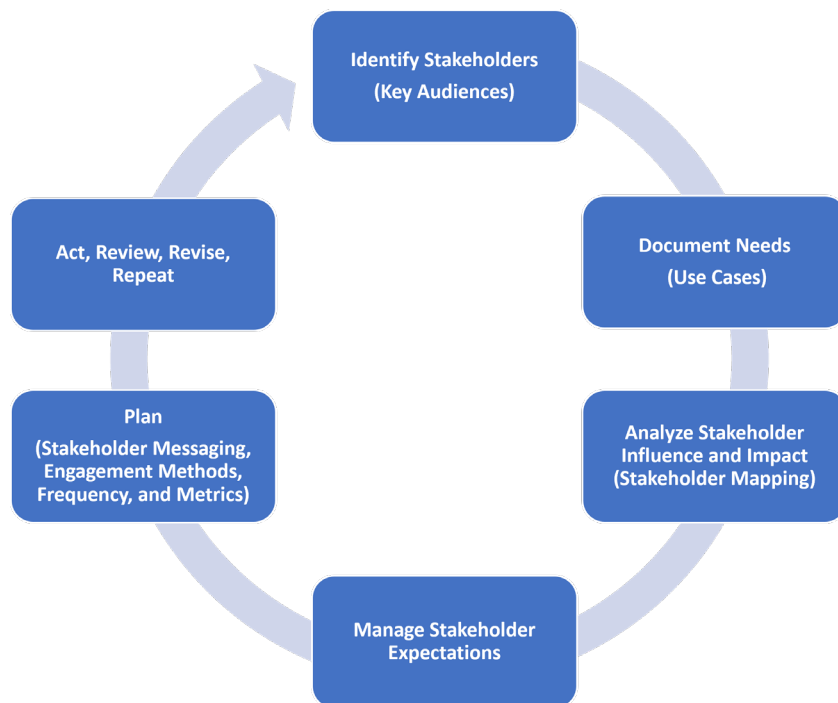
Figure 1. Stakeholder Evaluation Mapping to Plan Outreach Levels for Program Impact

### Stakeholder Mapping to Maximize Impact



Once this step is completed, stakeholder engagement planning would follow a cycle of continuous action and refinement conducted through stakeholder management. Figure 2 depicts the stakeholder management cycle. It simplifies the project’s Base Period strategy without tying work to discrete phases, much like the “Plan-Do-Study-Act” model of iterative design and management AHRQ uses for process improvement.<sup>16</sup>

**Figure 2. Stakeholder Management Cycle in an Engagement Plan**



## **Assemble a Stakeholder Champions Group**

Most stakeholders want to contribute to programs they deem important, and they want to be considered an equal partner whose contributions matter to the program owners. Because not all stakeholders will require constant or intensive management, understanding each stakeholder’s complexities is the basis for all planning and execution exercises, and a crucial benefit of stakeholder mapping.

When certain stakeholders are exceptionally committed to the organization and the project’s success (high interest, high influence), they can become the basis of a small, informal “champions group” of individuals who regularly champion, or endorse, AHRQ, CEPI, and advancements made by the organization. They can be internal to AHRQ (e.g., CEPI staff, AHRQ workgroup or advisory panel members, research applicants, research award grantees) or external (e.g., user-group representatives named by Congress in PCOR initiatives funding reauthorization,<sup>17</sup> high users of CEPI evidence who trust and value AHRQ’s mission, Federal or State agencies and departments who use AHRQ evidence or generate similar PCOR evidence for their stakeholders’ use, advocacy organizations, health plan technology assessment groups or coverage determination groups, technology vendors, or app developers).

Unlike a formal working group or advisory panel, champions could serve as an occasional sounding board to solicit potential program ideas or structural changes with insights on how public audiences may react to these proposals. AHRQ could apply these insights to modify the

ideas internally before making them public, or to proactively prepare strategies and materials to communicate effectively with audiences about the program proposals.

Champions can serve as first-hand CEDAR and AHRQ advocates by speaking to larger groups and professional connections, providing a persuasive message that may not be feasible or appropriate for a government representative to deliver. By building enthusiasm within a smaller, highly invested group, CEPI can empower its champions to expand the pool of interested user groups as an extension of other AHRQ efforts. How champions react to various messages or delivery methods and channels can inform how CEPI and AHRQ craft core messages and align them to effective delivery tools (e.g., email, blog posts, web-based briefing papers, webinars, town halls, organization workgroup presentations) that resonate with each unique audience.

## **Design a Streamlined Stakeholder Engagement Plan**

Once CEPI and AHRQ finalizes goals for CEDAR or an alternative evidence-dissemination tool, pursuing appropriate opportunities to achieve them will become clearer. CEPI should develop and implement an informal, internally managed plan to guide future outreach activities. This plan can crystallize how CEPI interacts with its key audiences, as well as inform future budget and resource allocation decisions.

A streamlined plan incorporates three components: 1) clear goals, 2) key initiatives and responsibilities to achieve those goals, and 3) a flexible “roadmap” (i.e., an action plan timed to accomplish milestones). Structuring these components provides critical information to help prioritize work, determine appropriate resources, and measure success and/or recognize a need to recalibrate activities. This approach can be scaled at will to modify tactics and compile resources, while continuing to pursue a defined goal. Additionally, the plan should be informal and managed by CEPI staff directly to preserve internal accountability and maximize policy decision-making flexibility. CEPI staff will enjoy the resilience and nimbleness to assign staff roles and responsibilities, choose how to track milestones or outcomes, and decide whether these relationships matter more than the feedback quality obtained from alternate engagement methods.

A stakeholder management plan provides a framework for engaging with internal and external audiences alike. In contrast with a generalized awareness campaign, most stakeholder management balances soliciting feedback with protecting the program from negative influence or apathy. By designing the framework and a roadmap, CEPI staff can assess progress on the desired outcome goal and manage stakeholder (and Agency) expectations, while developing deeper relationships. This is the missing component from the project’s outreach and communications plans. A roadmap that aligns with expected milestones and target dates supports accountability by tracking resource adequacy and progress to realizing project goals.<sup>18</sup>

The project found that direct engagement was effective in raising awareness of CEDAR’s purpose, as well as eliciting useful feedback to refine the API. Future stakeholder management

plans should start with CEPI reviewing outreach results and conduct an audience prioritization to clearly define which groups are most likely to use CEDAR, as well as which groups would benefit from new outreach. Then, CEPI can determine the optimal frequency, timing, messaging channels, and expected outcomes from consistent outreach to these audiences. Sustained relationships can support continued stakeholder trust in AHRQ, nimble CEPI and overall Agency decision making, and enhanced confidence that AHRQ's PCOR evidence and access tools are delivered to the right audiences, who use them as intended.

Stakeholder engagement is based on ongoing and iterative feedback. Often, it is simpler to conduct an awareness campaign through generalized information that distributes the same message through materials delivered broadly to various audiences. The project discovered that a more effective method to achieve CEPI's goals was through targeted messaging to specific audiences, emphasizing how CEDAR might align with different interests. Future CEPI outreach should conduct engagements through outreach methods tailored to stakeholder group, as well as to the individual of interest. This outreach needs to be proactive, as relying on the community to champion a new tool is not feasible until the tool is well established. Active stakeholder management requires more effort to achieve impact, but ongoing dynamic communication with target end users results in activated advocates who fully support the project goals and endorse the end product.

A communications plan that aims to build trust and sustain relationships with the intended audience—and encourage them to act *because* of the information shared in outreach—cannot be designed separately from a stakeholder engagement plan. Evaluation metrics should be developed and reviewed regularly to decide whether expanded communications or engagement are needed. Measures should evaluate positive and negative reactions alike to assess whether stakeholders have changed position within the stakeholder mapping matrix.

Because communications materials can be challenging to maintain, produce, and distribute throughout the engagement schedule, it often is necessary to galvanize invested stakeholders to serve as key dissemination partners. The CEDAR project created several communications products (e.g., informational flyer or handout, informational graphics, conference PowerPoint presentations and posters) to explain the concept behind CEDAR, as well as the technical details about the API's specifications. Each product can be used in conversations with specific audiences, depending on the level of interest and knowledge related to CEDAR. These are foundational materials CEPI can use to continue or initiate conversations with individuals with a wide variety of knowledge about CEPI resources, APIs, and PCOR information in general. Working with CEDAR's champions, CEPI can identify gaps in existing messaging to knowledgeable audiences or identify messages that resonate with certain groups. These insights should inform AHRQ's future efforts (e.g., identification of champions, ongoing community engagement with a CEDAR newsletter, updating communications materials, blog posts posted to CEPI's website, such as "Top Tips to Improve Search Results Using the CEDAR Demonstration UI and Find the Information You Need") that drive additional interest in CEPI evidence and the

CEDAR tool. Champions could also recommend communications products or informational blasts centered on specific messages or audiences they aim to reach using their own outreach efforts (e.g., social media posts about a specific CEDAR feature, static messaging, blog posts sponsored by their organization). These third-party communications may further increase the community's interest in CEDAR, resulting not only in further awareness and use of the tool, but also in additional recommendations for future CEDAR improvements. Champions also can advise CEPI about which messages, communications products, and delivery methods result in positive responses from their colleagues and contacts; these suggestions may accelerate AHRQ's development of outreach campaign components. Through their conversations within their networks, champions can also surface potential users' reticence toward CEDAR and help identify technical or other solutions that CEPI could consider for the CEDAR project.

This tactic reinforces the validity of developing a panel of stakeholder champions to advise the project. While AHRQ frequently integrates working groups and advisory panels into its programs, the champions approach is slightly different, as there is no formal commitment, and champions participate as time and interest allow. CEPI likely would ask champions to contribute in differing ways: soliciting specific advice and requesting assistance or engagement in varying areas, based on the champion's interest and expertise. Applying a champions approach, CEPI can accelerate its informal engagement strategy that encourages ongoing knowledge of the environment and advises on beneficial changes to the engagement strategy and messaging.

A stakeholder engagement plan and companion roadmap will inform CEPI and AHRQ of additional ways to expand and improve access to all its resources. For example, implementing these outreach recommendations may lead to identifying current research gaps that could be addressed through new grants aiming to increase the value of CEPI information. Further, CEPI outreach may establish relationships with audiences who would like to access existing CEPI or other AHRQ materials but do not yet know how to do so. Appendix C provides additional detail about recommended strategies, actions, and potential impacts that may help inform the basis of any future stakeholder engagement planning effort.

Table 1 compiles key findings discovered during the project, paired with recommendations for addressing them in future activities.

**Table 1. Recommendations to Address Key Findings**

Key Findings	Recommendation
Stakeholders' input on <i>how</i> the CEDAR API could be built helped construct a functional API but did not address <i>whether</i> the stakeholders would use CEDAR.	Implement an outreach plan to identify stakeholders' needs and their preferences for accessing CEPI resources.
Methodical analysis of expected user groups distilled CEDAR's potential audience to a tighter set of target end-user types likely to consider CEDAR adoption, based on an appreciation of AHRQ's reputation for evidence-based information.	Assess potential key audiences to select groups open to AHRQ outreach or willing to learn more about AHRQ.
Outreach to individuals through personalized messaging or existing relationships was more successful than relying on broadcast outreach and messaging through large conferences.	Develop and implement a stakeholder engagement plan that emphasizes building and strengthening personalized relationships through smaller settings and regular conversations.
Participation in standards development organization workgroups and connectathons generated less feedback to test CEDAR's interoperability and standards compliance than direct Pilot activities.	Monitor standards development and implementation changes via sustained "lightweight" workgroup participation to track future PCOR evidence retrieval and integration methods, and to identify potential opportunities for CEDAR uptake and improvements.
Listening to presenters and attendees at CDSiC Annual Meeting identified new audiences—including patients, caregivers, and patient advocacy organizations—as potential important new user groups for CEDAR and its evidence.	Evaluate whether growing availability of CDSiC resources, and new opportunities for patient use of CEPI evidence, warrant changes in outreach targets to meet user needs in evidence availability and dissemination.
Outreach to recruit focus group participants helped identify several individuals with deep commitment to AHRQ future success overall, as well as a willingness to provide actionable feedback about CEDAR.	Establish a Champions Group to provide timely informal feedback and serve as field advocates for CEPI and its resources.
Individuals that have existing experience with CEPI resources and research processes have strong overall trust in AHRQ.	Build on AHRQ's high trust factor with regular outreach engagement and education campaigns that recognize stakeholder interest in CEPI programs and policies around evidence development.
A communications plan to reach stakeholders with varying interest in AHRQ evidence or knowledge about CEPI resources requires coordinated messaging and outreach approaches that resonate with and drive action by each stakeholder.	Develop, implement, refine, and track impacts of a "toolbox" of CEPI-specific messages, communications products, and communicators (spokespeople or product writers) tailored to specific audiences with varying practices in how they use CEPI resources and delivered through their preferred methods.
The inability to evaluate the quantitative and qualitative success of outreach activities led to the team continually redesigning messages without clear evidence that they were driving interest in CEDAR and increasing use.	Create a stakeholder engagement plan that sets implementation milestones, metrics, and accountability responsibilities for each CEPI or project team member to manage resources and track progress toward CEPI goals.

Key Findings	Recommendation
<p>Outreach activities were designed to achieve specific, limited outcomes.</p>	<p>Structure outreach goals to gather information about and responses to foundational goals of the project, as well as specific outcomes. Assess stakeholders' views on the relevance and clarity of those goals, as well as to capture and track their actions and support for the overall project. Revise project tactics as necessary to achieve overall goals, and revisit original goals when considering related or successor projects.</p>
<p>CEDAR indexes evidence developed through AHRQ and the USPSTF; pilot testing identified that including additional findings may make CEDAR more appealing to end users.</p>	<p>Consider partnerships with other aligned Federal agencies and external organizations to facilitate dissemination of PCOR findings to desired target end users.</p>
<p>Activities within an outreach plan can be broadly characterized as opportunities to deliver messages to increase awareness and encourage action from audiences, as well as those to solicit feedback from them or assess whether or not the message delivery resulted in the desired actions, each providing information that can be used to adapt or change program components and future messaging. These have different techniques, goals, and benefits to the project.</p>	<p>Develop an outreach plan that supports both delivering information to and eliciting information from potential users, and identify which type of engagement (e.g., talking points used to inform participants, leading questions to encourage feedback, or both) must occur at each outreach activity (e.g., conference, event, publication/posting) to achieve one or more outreach goals for audience participation and response.</p>



## Appendix A. Abbreviations and Acronyms

Abbreviation or Acronym	Definition
AAFP	American Academy of Family Physicians
ACA	Patient Protection and Affordable Care Act of 2010
AHRQ	Agency for Healthcare Research and Quality
AMIA	American Medical Informatics Association
API	Application Programming Interface
App(s)	Application(s)
CDS	Clinical Decision Support
CDSiC	CDS Innovation Collaborative
CEDAR	CEPI Evidence Discovery And Retrieval
CEDAR UI	CEDAR Demonstration User Interface
CEPI	Center for Evidence and Practice Improvement
EBM	Evidence-Based Medicine
EHC	Effective Healthcare Program
EHR	Electronic Health Record
FAIR	Findable, Accessible, Interoperable, and Reusable
FEvIR	Fast Evidence Interoperability Resources
FFRDC	Federally Funded Research and Development Center
FHIR	Fast Healthcare Interoperability Resources
HHS	Department of Health and Human Services
HL7	Health Level Seven
IP	Internet Protocol
IT	Information Technology
PCOR	Patient-Centered Outcomes Research
PCORI	Patient Centered Outcomes Research Institute
PCORTF	Patient-Centered Outcomes Research Trust Fund
RI	Reference Implementation
SME	Subject Matter Expert
UI	User Interface
USPSTF	U.S. Preventive Services Task Force

## Appendix B. CEDAR Searches

Figure 3. Searches by Date July 2022 – July 2023 Using CEDAR Demonstration User Interface

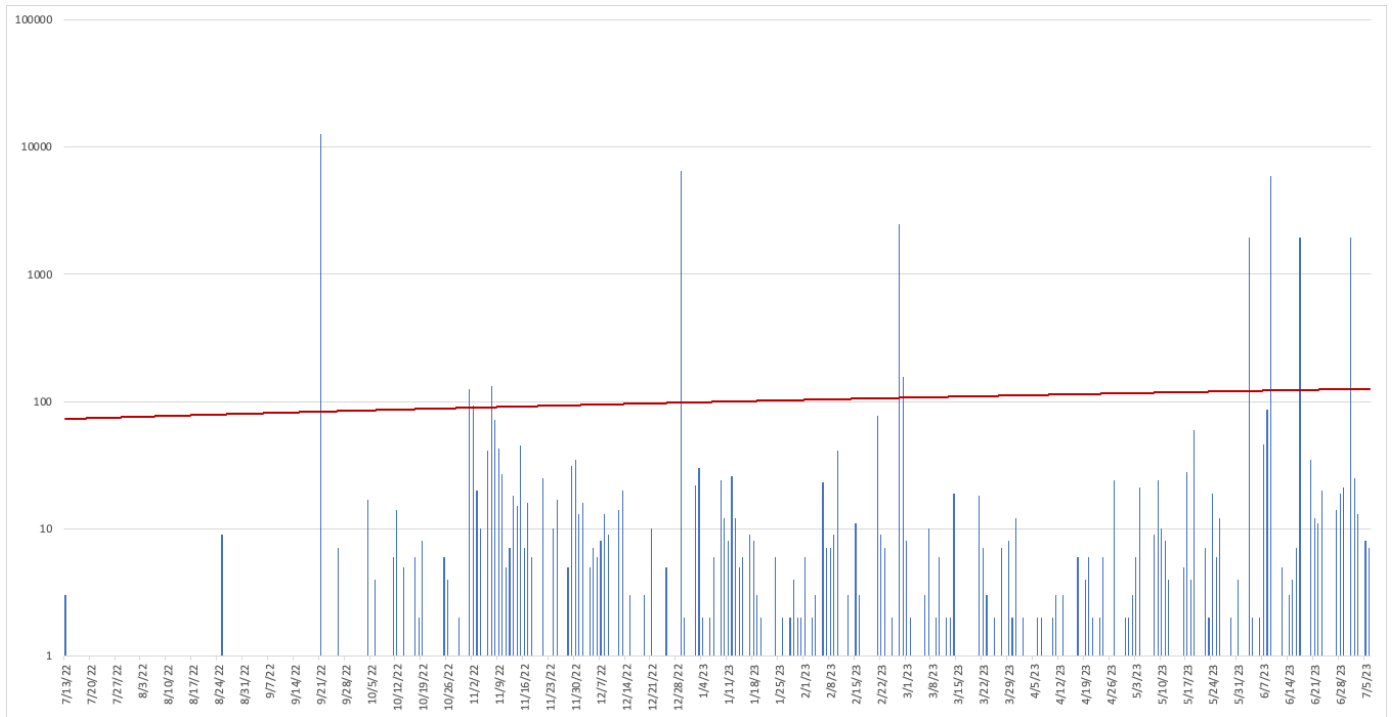


Figure 3 shows the number of searches per day between July 13, 2022, and July 5, 2023, using a log y axis so that high peaks would not hide the detail for more-regular days. Three activities may have led to upticks in the Demonstration UI's use:

- American Medical Informatics Association Annual Conference, November 4 – 7, 2022
- CDSiC Annual Meeting, May 16 – 17, 2023
- Option Period Pilot preparation for kickoff, May 22, 2023.

## Appendix C. Outreach Planning

Table 2 lists engagement strategies that may guide AHRQ’s future outreach efforts and resource allocations. It describes the potential impact for activities applicable to each topic area.

**Table 2. Outreach Opportunities for Future CEDAR and AHRQ Engagement**

Topic	Recommended Strategies	Activities	Potential Impact
Engage Key Stakeholders	Leverage external stakeholder partners for guidance and market insights through ongoing and proactive engagement.	<p>Categorize each partner (according to their need to access CEDAR-indexed evidence) as primary, secondary, or infrequent audiences for AHRQ outreach.</p> <p>Conduct outreach with partners identified as most likely to adopt CEDAR, most likely to support AHRQ through delivery of actionable information, and willingness to engage frequently over time.</p>	<p>Glean information from groups most likely to use AHRQ evidence to learn how they prefer to access and apply the evidence.</p> <p>Expand AHRQ relationships by categorizing impact level on Agency decisions and whether to commit to long-term, bidirectional communications and engagement.</p>
Reinforce Trust	Build on the foundation of AHRQ’s reputation as a trusted entity.	<p>Engage AHRQ champions group of high-impact, high-engagement individuals and organization representatives to provide guidance on proposed actions through a decision filter (e.g., whether it will enhance, restrict, or have limited impact on AHRQ’s reputation).</p> <p>Solicit insights that can inform future CEDAR direction, as well as additional current or contemplated AHRQ priority goals.</p>	Reward users’ trust in AHRQ through seeking their assistance in transmitting AHRQ messages and in soliciting their opinions.
Expand CEDAR Audience to Directly Include Patients, Caregivers, or Consumers	Work with CEPI repository owners (and potentially with other government and private-sector evidence generators) to learn whether, and how, CEDAR could serve a more patient-facing role.	<p>Continue indexing CDSiC and other CEPI repositories for consumer-relevant topics.</p> <p>Explore ways to make information more accessible to consumers through plain-language summaries, hyper-segmented indexing, semantic, or other methods.</p>	Position CEDAR as a method for individuals to inform their health decision making and position AHRQ as a source of information relevant and accessible to patients.
Explore New Platforms to Adopt Current CEDAR or to Improve CEDAR	Investigate technological improvements that can improve CEDAR’s integration or usability.	Collaborate with organizations such as Ovid, application stores hosted by electronic health record (EHR) developers, and user-interface developers to make CEDAR API easily adopted and integrated into professional workflows and practice patterns.	Expand CEDAR’s usability for intended audiences.

## Appendix D. Outreach Communications

The following materials describe ways AHRQ might connect with a wide variety of audiences (within the government, as well as the public) who have varying levels of familiarity with AHRQ, its mission, and CEPI's goals. Along with succinctly describing AHRQ activities, this messaging will need to address stakeholder informational needs in ways that resonate with them and inspire confidence that AHRQ values its engagement with them. Communications should be tailored to each specific audience; the team should continually refine these messages throughout the campaign to enhance receptivity and encourage actions that align with AHRQ's desired outcomes. The materials included here are representative, but not inclusive, of potential messaging.

AHRQ can consider the following talking points to initiate conversations with individual stakeholders or address audience questions. They are companion materials to leading questions designed to solicit information from key audiences.

Based on reactions and responses from stakeholder audiences, AHRQ can identify topic areas to create new or enhanced educational materials, more comprehensive messages, and/or background information that should be included in other resources, such as grant applications or other funding opportunities, and training programs. Future work can tailor talking points and leading questions for different stakeholder groups to structure the framing of the problem statement and CEDAR's provided solution, according to individual stakeholders' interests. These conversations should lead to better informed stakeholder awareness and opportunities for new insights to support AHRQ program management and strategy.

**Talking Points** describe CEDAR specifically, and CEPI evidence accessibility enhancements more generally. Several of these messages were used during the CEDAR project; others are offered to inspire additional message development for use in future stakeholder conversations as CEPI conducts outreach to new and existing audiences.

- AHRQ disseminates patient-centered outcomes research (PCOR) findings through clinical decision support (CDS) into clinical practice.
- AHRQ's Center for Evidence and Practice Improvement (CEPI) has created resources and programs that make PCOR findings available.
- The CEDAR project includes several different sources of indexed information. These include the Systematic Review Data Repository, Evidence-based Practice Centers, the Effective Health Care Program, CDS Connect, and the U.S. Preventive Services Task Force. In the past, AHRQ also managed the National Guideline Clearinghouse, although it is now not active.
- Many people interested in using PCOR evidence find it challenging to find and access this evidence directly from individual CEPI repositories.

- AHRQ understood that users found it difficult to automate searches within each CEPI repository, and those iterative, individual searches were slow.
- Searching each repository independently meant it was too easy to miss CEPI content.
- CEPI's goal is to align AHRQ data and PCOR evidence with FAIR principles. This can help make AHRQ's information more findable (easy to locate), accessible (easy to retrieve), interoperable (compliant with widely adopted standards), and reusable (usable in different settings).
- Initially, AHRQ elected to create an application programming interface (API) that uses software specifications built on standards developed through the Fast Healthcare Interoperability Resources (FHIR) to exchange electronic healthcare data.
- This API, named CEDAR, was created to allow other health IT developers to integrate AHRQ CEPI research findings into existing electronic systems for use by clinicians, researchers, policymakers, patients, and others.
- AHRQ's goal was to allow clinicians and patients to have real-time access to evidence for decision making, as well as to support researchers and others in reviewing evidence when crafting clinical guidelines, making healthcare and coverage policies and decisions, and engaging in similar activities.
- AHRQ conducted the project not only to create the API, but also to incorporate feedback from key stakeholders when developing and testing it.
- AHRQ pilot-tested the API in two phases—first during development, and later in a real-world setting—to assess its ability to deliver CEPI content in alignment with FAIR principles.
- Feedback from stakeholders was critical, as the project team evolved the CEDAR API through multiple versions and open-source specifications.
- The project discovered several findings, including stakeholders' interest in a freestanding demonstration user interface that would help developers and others understand CEDAR.
- The CEPI project also worked to solicit stakeholder feedback through various outreach methods, including conference presentations, small group conversations with subject matter experts, and discussions with work group members who are involved in standards development to accelerate FHIR. Each method generated rich feedback that helped the project team continually refine CEDAR and modify how it interacted with stakeholders and others.
- CEPI understands the value guidelines developers and users place in AHRQ evidence and its repositories. CEDAR was a method to serve those audiences by indexing evidence in a way that could facilitate additional guidelines development, among other uses, to continue advancements in PCOR and CDS for users.
- AHRQ will review CEDAR project findings and continue to evaluate how to make its growing CEPI repository libraries meet FAIR principles, as well as deepen the evidence content available.

- CEDAR findings also will be reviewed to determine whether changes in CEPI repositories can make content more computable through new technology innovations and standards advancements.
- AHRQ appreciates the trust users hold for its evidence and will continue to pursue stakeholder insights to inform programs and policies aligned to AHRQ’s mission.

**Leading Questions** obtain stakeholder insights on needs and interests in evidence, allow the staff member to learn about emerging technologies and standards that improve real-time evidence retrieval and use, and provide rationale for future AHRQ program enhancements in improving evidence retrieval by key audiences. Several of the following questions were developed to initiate conversations with developers, thought leaders, and knowledge managers during an HL7 “Birds of a Feather” session proposed for September 2023.

- What do you work on or know about that might relate to CEDAR?
- Does your professional work require using research evidence generally, or specifically using AHRQ evidence and data? If so, how are those data used?
- Do you work in a context where searching for evidence is relevant?
- What is your current approach for searching for evidence?
- Do systems that you work with make use of searching for evidence, or could use something similar?
- What systems could benefit from an API like CEDAR?
- Do you have experience doing things similar to what CEDAR intended to provide?
- What lessons learned or successes could you describe about your API development, implementation, or other experiences in evidence retrieval, information accessibility, or other activities?
- CEDAR was built to index AHRQ CEPI data, and CEDAR is an open-source platform. Do you work in any contexts where the open-source CEDAR project would be useful?
- The CEDAR API didn't get traction with its intended users. Do you have ideas for methods that can improve access to AHRQ evidence in ways that are more relevant to how you use PCOR findings?
- What changes could make CEPI resources better meet FAIR principles?
- What should CEPI prioritize for the next 3 to 5 years to improve CEPI evidence retrieval and use?
- What future demonstrations or pilots would you recommend AHRQ develop to explore evidence retrieval?
- Are there any evidence users AHRQ has not considered as an important audience to reach?
- CEDAR is based on FHIR standards. Are you aware of other emerging interoperability conformance standards in development or under consideration that should be explored?

- How can advancements in artificial intelligence and large-language models be applied to evidence retrieval? What steps should AHRQ take now to prepare for those advancements?
- What are the most common ways researchers, clinicians, policymakers, and other audiences use evidence retrieval products? What disappoints these users about how they use such products?
- If you could change one thing about how AHRQ disseminates CEPI evidence, what would that be?

During outreach activities, stakeholders often asked the project team general and specific questions. The communications materials developed for the project often directly addressed them; at other times, they were answered in followup conversations. The following list represents the types of questions that stakeholders asked:

- What is CEDAR?
- Why did AHRQ build CEDAR?
- Who was CEDAR designed to serve?
- How does CEDAR work?
- What standards does CEDAR use?
- Does CEDAR index all AHRQ evidence and resources?
- Is there a fee to use CEDAR?
- What audiences did AHRQ reach out to when designing CEDAR?
- Why would I use CEDAR instead of my current processes?
- Is the CEDAR evidence computable?
- What are CEDAR's main competitors?
- Who do I need to work with to create an app to use CEDAR?
- What development resources are available to me and my organization to use CEDAR?
- Will CEDAR grow to include more evidence?
- Will the National Guidelines Clearinghouse become active again?

## Appendix E. References

<sup>1</sup> Patient Protection and Affordable Care Act, Public Law 111-148, March 23, 2010. Sec. 6301 (“Dissemination and Building Capacity for Research”).

<https://congress.gov/111/plaws/publ148/PLAW-111publ148.pdf>.

<sup>2</sup> Further Consolidated Appropriations Act, 2020, Public Law 116-94, December 20, 2019.

<https://www.congress.gov/116/plaws/publ94/PLAW-116publ94.pdf>.

<sup>3</sup> CMS Alliance to Modernize Healthcare (The Health FFRDC). AHRQ CEDAR: Final Project Report 2022. Prepared under Contract No. 75FCMC18D0047. AHRQ Publication No. 22-0064-1-EF. Rockville, MD: Agency for Healthcare Research and Quality; September 2022.

<sup>4</sup> HL7, FHIR for FAIR – FHIR Implementation Guide 22, “CEDAR – Making evidence more FAIR.” <http://build.fhir.org/ig/HL7/fhir-for-fair/cedar.html>).

<sup>5</sup> CEDAR conceptual framework, AHRQ Clinical Decision Support. <https://cds.ahrq.gov/cedar/>.

<sup>6</sup> U.S. Food and Drug Administration, Patient Engagement Advisory Committee, content updated October 13, 2020. <https://www.fda.gov/advisory-committees/committees-and-meeting-materials/patient-engagement-advisory-committee>.

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<sup>8</sup> Edelman Trust Institute, “2023 Edelman Trust Barometer Special Report: Trust and Health.” <https://edelman.com/trust/2023/trust-barometer/special-report-health>.

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<sup>12</sup> Patient Centered Outcomes Research Institute, “Patient and Family Engagement: Improving Health and Advancing Equity,” National Partnership for Women and Families. December 2021. <https://www.pcori.org/sites/default/files/NPWF-Patient-Family-Engagement-Report.pdf>.

<sup>13</sup> Ibid.

<sup>14</sup> AHRQ, PCOR Strategic Framework Cross-Cutting Strategies to Advance Patient-Centered Outcomes Trust Fund Priorities. June 2023. <https://www.ahrq.gov/pcor/strategic-framework/cross-cutting-strategies.html>.

<sup>15</sup> Robert Otto Valdez, Ph.D., M.H.S.A., and Karin Verlaine Rhodes, M.D., M.S. “With Guidance from the Field, AHRQ Launches an Ambitious Strategy for Patient-Centered Outcomes Research.” AHRQ Views: Blog posts from AHRQ leaders, July 11, 2023. <https://www.ahrq.gov/news/blog/ahrqviews/ahrq-launches-pcor-strategy.html>.

<sup>16</sup> AHRQ, Health Literacy Universal Precautions Toolkit, 2nd Edition, “Plan-Do-Study-Act (PDSA) Directions and Examples,” content last reviewed September 2020. <https://www.ahrq.gov/health-literacy/improve/precautions/tool2b.html>.

<sup>17</sup> Further Consolidated Appropriations Act, 2020, Public Law 116-94, December 20, 2019. <https://www.congress.gov/116/plaws/publ94/PLAW-116publ94.pdf>.

<sup>18</sup> Nadia Schadlow, “The Forgotten Element of Strategy,” The Atlantic, June 22, 2023. <https://www.theatlantic.com/ideas/archive/2023/06/us-national-security-strategy-pentagon-time/674472/>.