

AHRQ CEDAR

An Environmental Scan to Inform the Development of CEDAR (2023)

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Executive Summary

The Agency for Healthcare Research and Quality (AHRQ) and its Center for Evidence and Practice Improvement (CEPI) requested the assistance of the Centers for Medicare & Medicaid Services (CMS) Alliance to Modernize Healthcare Federally Funded Research and Development Center (the Health FFRDC), operated by The MITRE Corporation (MITRE), to develop the CEPI Evidence Discovery And Retrieval (CEDAR) Reference Implementation (RI).

As part of this effort in 2020, MITRE prepared an environmental scan (ES20) that was a foundational step of information gathering for the development of the RI. This RI was developed to demonstrate the use of a standards-based application programming interface (API) to find, access, and use patient-centered outcomes research (PCOR) evidence from multiple existing repositories. The initial RI also demonstrates how PCOR data within AHRQ repositories can align with Findable, Accessible, Interoperable, and Reusable (FAIR) data principles. In 2022, the CEDAR RI was released as an open-source, standards-based tool that provides developers the ability to integrate AHRQ resources directly into existing systems. Researchers, clinicians, patients, and other users who rely on AHRQ can access the information that they seek through other third-party applications using CEDAR.

This document, Environmental Scan 2023 (ES23), is the next step to inform how to extend the CEDAR RI capabilities, including increased functionality, better alignment with user goals, and improved usability. It updates ES20 by capturing evolutions in the CEDAR development team's understanding and knowledge of multiple PCOR resources, as well as reveals gaps in knowledge, infrastructure, and technology to access these resources. Using findings from ES23, CEDAR can improve the way clinicians, patients, and other end users can leverage the RI to obtain data helpful in making healthcare decisions. The reader is encouraged to include a review of ES20 while reading this document.

ES23 includes analysis of informal interviews, literature reviews, and reviews of industry-leading practices most relevant to CEDAR's operating requirements and use. This document captures these activities and their impacts in the form of analysis, identified risks, and recommendations that can be leveraged for future versions of the CEDAR RI.

Based on these findings, MITRE suggests the following near-term and long-term recommendations for AHRQ's consideration.

Near-Term Recommendations

- **Augment FAIR assessment and the C-FAIR tool with the inclusion of an assessment using Transparency, Responsibility, User Focus, Sustainability, Technology (TRUST) principles.** To enhance the FAIR assessment of CEDAR, consider expanding it to include an assessment of TRUST.
- **Target users and use cases when updating the RI.** To optimize results of the Pilot planned for 2023, focus on a specific set of users and associated use cases to maximize the benefit of CEDAR for that subset of needs. Correct identification of the largest segment of users and associated use cases or needs will be key to driving adoption of CEDAR.

- **Establish enhancement priorities for CEDAR.** Prioritize goals for CEDAR development and expansion based on uses cases and target user groups. Continue to seek understanding of different needs and “pain points” associated with the current use of CEPI repositories (and web-based data repositories in general), and incorporate those lessons when enhancing CEDAR RI’s capabilities. This may include tailoring features and capabilities of the API to meet these needs of those groups; this feedback also may drive decisions regarding CEDAR expansion (e.g., to index additional information from additional AHRQ repositories).
- **Differentiate CEDAR from other resources.** Quantify the key differences and unique qualities that CEDAR separates from other tools used to access PCOR information.
 - **Emphasize the high-quality and high-reliability nature of the information indexed by CEDAR** (e.g., C-FAIR, government information sources).
 - **Illustrate CEDAR’s utility as a free tool that clinicians and researchers can access without a license or subscription.** Alternatives that offer equivalent access to trustworthy data are only offered through fee-based services.
- **Develop a “quick implementation kit” for CEDAR.** Develop a toolkit for efficient and easy integration of the CEDAR API into a user environment.
 - **Consider user interface options that allow users to sample the CEDAR data sets through a trial app or equivalent resource.**

Long-Term Recommendations

- **Broaden the information accessible through CEDAR.** Extend support for indexing beyond current CEPI repositories and PCOR information sets. Consider the inclusion of broader health information resources that are also of interested to clinicians.
- **Identify challenges or limitations with search capabilities currently built into to the repository’s native search features (i.e., the Effective Health Care [EHC] Program “Search EHC” search tool).**¹ Work with repository owners to assess interest in the use of the CEDAR RI or API capabilities as a replacement for their own search functions for their direct users.
- **Engage in industry working groups on TRUST.** In response to the growing interest in the trustworthiness of data and its origins, include a formal commitment to evaluating CEDAR’s trustworthiness with an augmented C-FAIR tool that includes TRUST principles.

¹ Evidence-based Practice Centers. Effective Health Care (EHC) Program [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US); 2017. Available from: <https://effectivehealthcare.ahrq.gov/about/epc>.

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1 Introduction

The Agency for Healthcare Research and Quality (AHRQ) and its Center for Evidence and Practice Improvement (CEPI) requested the assistance of the Centers for Medicare & Medicaid Services (CMS) Alliance to Modernize Healthcare Federally Funded Research and Development Center (the Health FFRDC), operated by The MITRE Corporation (MITRE), to develop the CEPI Evidence Discovery And Retrieval (CEDAR) Reference Implementation (RI).

AHRQ ensures that clinicians, researchers, and users of patient-centered outcomes research (PCOR) information have timely and efficient access to findings to support evidence-informed healthcare decision making. Additionally, when possible, AHRQ-disseminated PCOR information meets the Findable, Accessible, Interoperable, and Reusable (FAIR) data principles² for scientific data stewardship.

In 2022, MITRE developed the CEDAR RI that demonstrates how PCOR data housed within AHRQ repositories can align with FAIR data principles. This Environmental Scan 2023 (ES23) is the next step to extend the capabilities of the CEDAR RI through increased functionality, better alignment with user goals, and improved usability and user experience.

1.1 Background

The CEDAR RI was developed to facilitate easy and efficient access to PCOR data from disparate sources that end users can access across different technologies. As a first step to develop CEDAR RI, MITRE conducted Environmental Scan 2020 (ES20) to establish an understanding of existing PCOR data retrieval and to understand gaps in the knowledge, infrastructure, and technology.³ ES20 documented the landscape and maturity of existing standards, including the growing use of Fast Healthcare Interoperability Resources (FHIR) as a standard for healthcare data exchange.⁴

During the base period (September 2020 – September 2022), CEDAR RI was built from key input from AHRQ CEPI repository leads and aligned to the FAIR data principles. Initially, the team prepared ES20 that was a foundational step of information gathering for the development of the CEDAR RI. This RI was developed to demonstrate the use of a standards-based application programming interface (API) to find, access, and use PCOR evidence from multiple existing AHRQ repositories. The initial RI also demonstrates how PCOR data within AHRQ repositories adheres to the FAIR principles.

In 2022, this CEDAR RI was piloted with the American Association of Family Physicians (AAFP) and modified based on pilot results. Later in the same year, the CEDAR RI was released

² Wilkinson, M., Dumontier, M., Aalbersberg, I. et al. “[The Fair Guiding Principles for Scientific Data Management and Stewardship](https://doi.org/10.1038/sdata.2016.18),” *Sci Data* 3, 160018 (2016). <https://doi.org/10.1038/sdata.2016.18>.

³ 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.

⁴ What is FHIR®? - Office of the National Coordinator for Health Information Technology (no date). What Is FHIR®? Office of the National Coordinator for Health Information Technology. Available at: <https://www.healthit.gov/sites/default/files/2019-08/ONCFHIRFSWhatIsFHIR.pdf>.

as an open-source tool that provides developers the ability to integrate AHRQ CEPI repositories directly into existing systems. Researchers, clinicians, patients, and other users who rely on AHRQ can access the information that they seek through other third-party applications using CEDAR.

1.2 Purpose

The purpose of this document is to provide updates to ES20. These updates will inform the refinement of the CEDAR RI by increasing understanding and knowledge of multiple PCOR resources, as well as reveal gaps in knowledge, infrastructure, and technology to access these resources. The CEDAR project can use the findings from this environmental scan to further develop an RI that demonstrates how clinicians, patients, and other end users can more effectively obtain data helpful for healthcare decisions. The reader is encouraged to include a review of ES20 while reading this document.

This document encompasses the following subject areas and assessment activities, as shown in Figure 1.

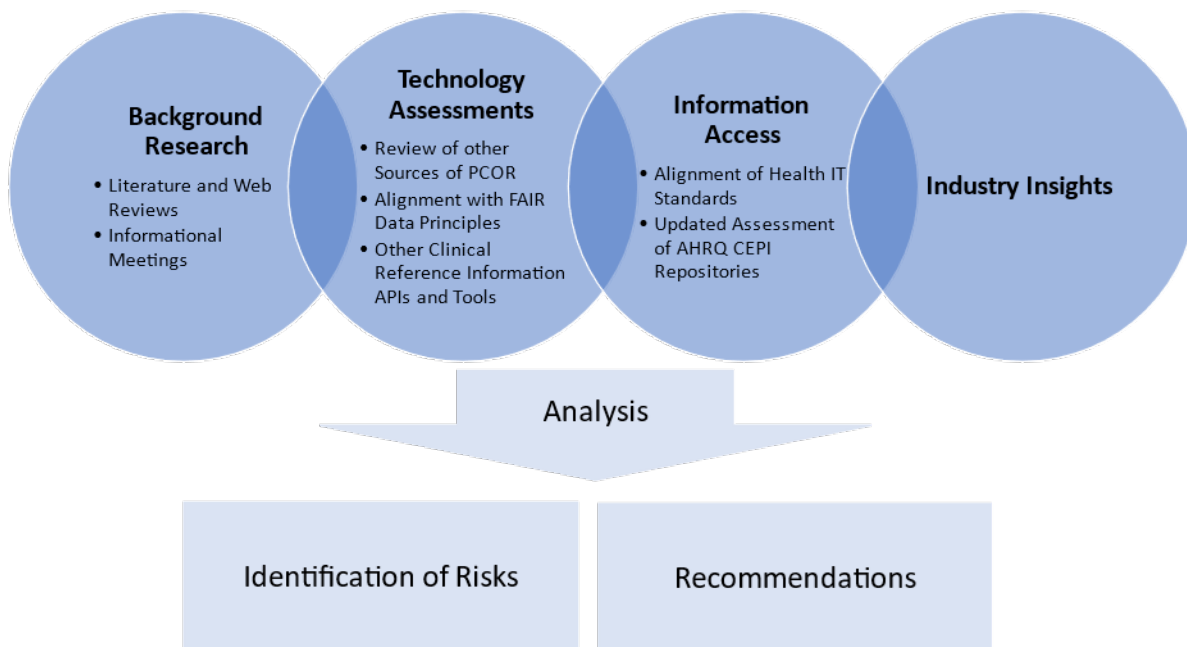


Figure 1: Environmental Scan Overview

- **Background Research** – These research activities include a broad selection of literature and web reviews, and informational meetings with subject-matter experts (SMEs). This material is covered within the Methodology, Section 2.
- **Technology Assessments** – The technology assessments review sources of PCOR and other health-related repositories, and assessment of FAIR data principles. This material is covered within the Methodology, Section 2.

- Review of Access to Information Sources – Review of applicable health IT standards, analysis of changes to technical specifications underlying each AHRQ CEPI PCOR repository, assessment of other application programming interface (API)-based tools for providing access to reference information for clinicians. This material is covered within the Methodology, Section 2.
- Industry Insights – Lessons learned from previous pilot activities, conversations with industry leaders in health IT, and feedback/engagement from conferences. This material is covered within the Methodology, Section 2.
- Analysis – Discussion and synthesis of the information gathered, spanning areas described in the previous sections. This analysis considered information available for possible inclusion in CEDAR, characterization of the potential users for CEDAR and the use cases that they may engage in, as well as some lessons learned from other tool and API implementation within the same health-related information space. This material is found in Section 3.
- Identification of Risks – Discussion of gaps that may impact development and implementation. Risks were identified throughout the course of the research by comparing currently available repository features and health IT standards to stated requirements. They are sorted for purposes of this document into technical and other, non-technical risks, and documented in Section 4.
- Recommendations – Recommendations, found in Section 5, were developed by the team based on research, CEDAR architecture needs, and their relation to and potential to mitigate identified risks. Recommendations are categorized as either near-term or long-term, based on feasibility and estimated timeframe for achievement.

1.3 Scope and Limitations

This ES23 is based on the work completed in ES20, updated to capture new findings and any industry developments in the use of open-source APIs. It does not address either the base period Pilot or a followup Pilot, although findings in this paper may inform those efforts.

2 Methodology

Activities completed to conduct this environmental scan included informal interviews, literature reviews, and reviews of industry-leading practices most relevant to CEDAR’s operating requirements and use. In addition, MITRE summarized these findings to develop a clear picture of API use and the FAIR data principles and trust landscape. These activities and their impacts were captured in this document as analysis, identified risks, and recommendations that can be leveraged for future versions of the CEDAR RI.

2.1 Background Research

2.1.1 Literature and Web Reviews

Literature reviews identified research and relevant subject matter areas by using electronic databases and search engines, such as Google, Google Scholar, and PubMed®. Literature reviews expanded to subject-matter-specific websites as necessary, such as in review of standards-focused content available from Health Level Seven (HL7®), Integrating the Healthcare Enterprise, and HealthIT.gov. Search terms varied according to research subject. Literature and web reviews were used in conjunction with research in several of the areas discussed here and, where applicable, specific information sources are identified. Details of key words and search protocols used for different literature searches can be found in Appendix A.3, Appendix C.1, and Appendix C.4.

2.1.2 Informational Meetings

Informational meetings—both internal to the AHRQ and MITRE working group (for the dissemination of information) and with external parties (to solicit insights and potential recommendations)—were established during the base period and continued through the Option Year of the CEDAR RI contract to collect and review insights from potential end users with an interest in PCOR data. Subject matter experts, AHRQ CEPI repository leads, and other potential stakeholders with an interest in PCOR all contributed in some part to deliberations on a review of the CEDAR RI, discussion of CEDAR feature development, and applicability to repository content. In addition to providing guidance on potential CEDAR RI development, relevant material from these meetings contributed to findings in the ES23 Section 3 Analysis and Section 5 Conclusions and Recommendations.

Additional potential PCOR and AHRQ CEPI repository stakeholders have been identified for ongoing outreach and engagement efforts.

2.2 Technology Assessments

ES23 updates include a review of other repositories of health information, CEDAR RI alignment with FAIR data principles, and a review of other clinical reference information.

2.2.1 Review of Other Repositories of Health Information

The MITRE team assessed ES20 to ensure that the information provided continues to represent current sources of PCOR information, and that other healthcare-related information about repositories remains accurate and complete. The *Library of PCOR Resources*⁵ webpage on AHRQ’s website states: “(AHRQ) provides this comprehensive Web library of patient-centered outcomes research (PCOR) resources to highlight the existing collection of PCOR projects conducted by public, private, nonprofit, and academic sources.” The MITRE team reviewed the team’s initial assessment of the existing *Library of PCOR Resources* webpage, conducted in ES20, and noted any changes to the current sources of PCOR information. Updated resources were compiled and included in Appendix C.1.

2.2.2 Alignment With FAIR Data Principles

A core goal of developing the CEDAR RI was to increase the alignment to FAIR data principles of the AHRQ CEPI PCOR repositories.⁶ The availability of tools to assess these data sources for alignment with FAIR, however, was limited when ES20 was conducted, thus the CEDAR team developed the CEDAR-FAIR (C-FAIR) tool as a method to assess a repository systematically and objectively for adherence to FAIR data principles.⁷ The CEDAR team intends to stay informed of new insights or recommendations offered in the FHIR for FAIR Implementation Guide and by the FHIR for FAIR project team to determine if changes should be considered to the C-FAIR tool for improvement.⁸

As the repositories indexed by the CEDAR RI evolve, such as through growth or updated technologies, the CEDAR RI will need to ensure continued alignment between CEPI PCOR repositories and FAIR data principles. Thus, the CEDAR team will conduct additional C-FAIR assessments to determine changes in FAIR alignment of the CEPI repositories. Before further C-FAIR assessments are conducted, the CEDAR team will ensure C-FAIR tool criteria remain aligned with the current state of FAIR data principles. For more information about C-FAIR, see Appendix A.

In addition to assuring a user that the digital artifacts accessed are high quality and reliable, a data repository must also ensure that the quality is preserved over time. Therefore, Appendix A also investigates the emerging role of Transparency, Responsibility, User Focus, Sustainability,

⁵ Library of PCOR Resources (2016). Agency for Healthcare Research and Quality, Rockville, MD. Available at: <https://www.ahrq.gov/pcor/library-of-resources/index.html>.

⁶ CMS Alliance to Modernize Healthcare (The Health FFRDC). AHRQ CEDAR: Final Report. Prepared under Contract No. 75FCMC18D0047. AHRQ Publication No. 22-0064- 1-EF. Rockville, MD: Agency for Healthcare Research and Quality. September 2022.

⁷ Guiding principles for findable, accessible, interoperable and reusable data publishing version B1.0 (2016) Force11. The Future of Research Communications and e-Scholarship. Available at: <https://force11.org/info/guiding-principles-for-findable-accessible-interoperable-and-re-usable-data-publishing-version-b1-0>.

⁸ Center for Evidence and Practice Improvement (CEPI) Evidence Discovery and Retrieval (CEDAR) - Making evidence more FAIR. (2022) FHIR for FAIR - FHIR Implementation Guide. Available at: <http://build.fhir.org/ig/HL7/fhir-for-fair/cedar.html>.

Technology (TRUST) principles for ensuring confidence in the information stored in data repositories.⁹

2.2.3 Other Clinical Reference Information Sources – APIs and Tools

Just as the CEDAR team looked at information sources and data repositories with a broader focus than just PCOR information, the team conducted a broad scan of the tools that clinicians are using to access clinical reference information. This tool assessment includes those tools that are used by clinicians to support their clinical knowledge base, clinical decisions, or activities.

A combination of SME conversations, web-based searches, direct interactions with tools, and literature searches were conducted to assemble a list of similar and potentially competitive or complimentary tools. The details of the information gathered from these efforts are included in Appendix C. The CEDAR team also considered the successes and challenges for API adoption in this same space using the same research techniques. These successes and challenges are summarized as a part of the analysis presented in Section 3.4.1.

2.3 Information Access

To ensure continued alignment with evolving health IT standards and changes in the CEPI repositories, ES23 evaluated technical and content updates to the repositories that interact with the CEDAR RI.

2.3.1 Alignment with Health IT Standards

Changes to standards used in CEDAR RI were reviewed for updates to requirements, tool evolution, and maturity, as measured by the FHIR implementation community. Alignment with health IT standards promotes interoperability and lowers barriers to widespread adoption by providing a single search interface over multiple different repositories of CEPI information. CEDAR RI uses FHIR resources related to evidence-based medicine and aligns with FAIR data principles. Appendix E presents an overview of changes to health IT standards, resources, and modules.

2.3.2 Updated Assessment of AHRQ CEPI PCOR Repositories

ES23 evaluated AHRQ CEPI repositories that have already been indexed for the CEDAR RI. The evaluation identified impactful changes to the repositories' data models and data schemas, and APIs, as well as the best approach for ensuring continued integration with the CEDAR RI. This technical analysis focuses on three aspects of each repository:

- Architecture describes how repository software is structured and provides insight into the interaction of a repository's data models and APIs.
- Data models and data schemas describe how a repository organizes artifact data, which is vital to mapping each repository's data model into CEDAR.

⁹ Lin, D., Crabtree, J., Dillo, I. et al. [The TRUST Principles for digital repositories](https://doi.org/10.1038/s41597-020-0486-7). Sci Data 7, 144 (2020). <https://doi.org/10.1038/s41597-020-0486-7>.

- APIs describe how data in a repository can be accessed and are important when building indexers that retrieve data from each repository.

2.4 Industry Insights

Lessons Learned from the AAFP Pilot – CEDAR conducted a pilot with AAFP in 2022 during the base contract period. The AAFP pilot effort developed a user interface (UI) to the CEDAR API, with the UI tailored to the specific needs of the AAFP membership. An unexpected finding from the previous pilot is the observation that some involved physicians used the AAFP-developed UI at the point of care. A summary of the key lessons learned from the 2022 Pilot that should be considered for the context of the next pilot can be found in Appendix B.1. For more detailed information about the lessons learned, the final report, *CEDAR Final Pilot Report*,¹⁰ can be found on the AHRQ CEDAR site.

Feedback from Health IT Experts – In addition to AAFP pilot user engagement, the MITRE CEDAR team held informal conversations with potential end users through its professional relationships using multiple communication opportunities to understand persistent and emerging user needs. This feedback helped identify possible use cases to support the CEDAR tool's continued evolution to maximize its capabilities and user benefits. Development of use cases can identify and define characteristics and differences between users so CEDAR can meet multiple users' needs.

MITRE also solicited insights from meeting participants attending the American Medical Informatics Association (AMIA) conference held in November 2022, specifically during presentations given by AHRQ and MITRE staff of the CEDAR API. The CEDAR team solicited meeting participants' perceptions of the purpose of CEDAR, its ability to rapidly index the repositories, and AHRQ programs, as well as overall impressions. The project team conducted qualitative information gathering through feedback portions of demonstrations sessions, engaged in dialogue about the recent and future directions of information tools for healthcare, and has compiled a summary of the information learned through these interactions in Appendix B.2.

¹⁰ CMS Alliance to Modernize Healthcare (The Health FFRDC). AHRQ CEDAR: Final Report. Prepared under Contract No. 75FCMC18D0047. AHRQ Publication No. 22-0064- 1-EF. Rockville, MD: Agency for Healthcare Research and Quality. September 2022.

3 Analysis

Central to ES23 are the relationships between the functional elements that provide access to PCOR data and the user interfaces that aid the flow of information. The orange arrows on Figure 2 illustrate the flow of information between the source (i.e., repository) and the destination (i.e., user) via a tool. For information to flow freely, several essential elements must be involved in the successful interaction—the API, the tool used to access the information (i.e., a mobile application or web browser) and the user interface. The API acts as a bridge between the source and tool, facilitating the communication and exchange of data between them. The tool UI provides a mechanism for users to interact with the tool and extract or view information. A very important logical relationship exists between repositories (i.e., information sources) and users; nevertheless, there is not a direct path between these two without tools.

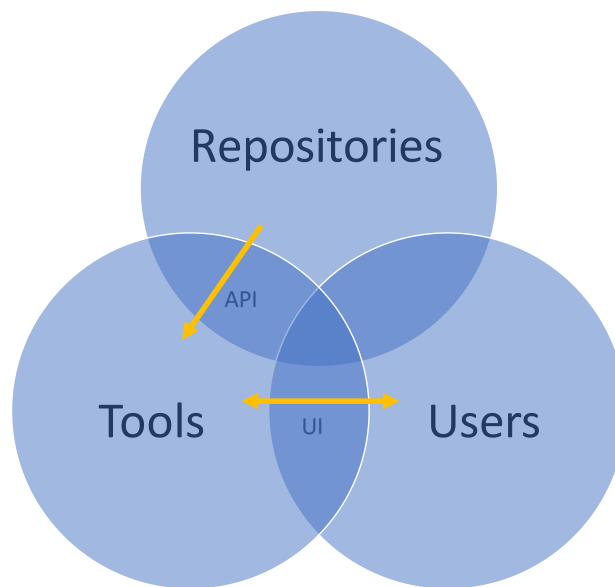


Figure 2: Relationship Between Environmental Elements

CEDAR is one example of a tool that provides that important connection between users and the CEPI repositories. Overall, CEDAR currently offers a web-based tool comprised of the RI and a demonstration user interface. The pilot activities in later 2023 must identify priorities for development decisions and managing the scope of CEDAR evolution.

Figure 3 depicts a generic Concept of Operations (CONOPS) showing how information flows between these elements. These include:

- Information sources or repositories (shown on the top).
- The technical means (depicted with an arrow for information sharing between repositories and tools).
- The tools, such as an application or web browsers, with a user interface for the presentation of information (far left).
- The users accessing the information (far right).

Each of these elements plays a unique role in information sharing.

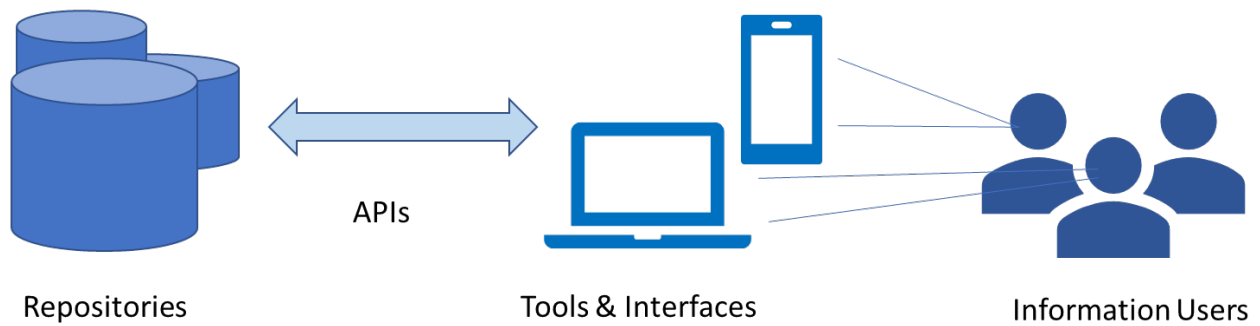


Figure 3: Functional Elements in Information-Sharing

In the case of CEDAR, this interaction is between CEPI repositories communicating via an API and a web browser-based reference implementation/user interface for CEDAR users. The specific interactions between these elements for CEDAR can be seen in the CONOPS diagram,¹¹ which is included in an overview of the reference implementation.

As a part of this scan, the CEDAR team included each of these functional elements into the methodology of materials researched and assessed. The team focused on identifying areas where changes to the characteristics of these elements have occurred since ES20 was performed. The team also looked beyond the set of elements specific to the CEDAR implementation, to consider how similar elements in the larger environment may be relevant, provide lessons learned, and indicate possible areas for future CEDAR expansion.

The following sub-sections synthesize changes to the available resources since the original environmental scan and consider change in the demand signals and technology capabilities available for integration into the CEDAR API and RI. They also summarize the findings of the research and analysis of this environmental scan. The details of the information assessed and the means used to collect that information can be found in the relevant appendices noted inline in this section. These findings will guide the design and implementation of pilot activities in 2023 and inform any potential risks to the pilot and long-term success of CEDAR RI.

This analysis focuses on elements of information sharing, including APIs, repositories, and end-user outputs. Analysis provided here is based on the information collected as a part of ES23 activities.

3.1 Analysis of Repositories

CEDAR RI indexes multiple current information sources provided through CEPI repositories. Additional PCOR sources of information were reviewed for their potential compatibility and as future repositories of interest. A comprehensive list of sources of health-related information is included in ES20 and captured in Appendix B of that document. Appendix C.1 of this document provides an update to that list.

¹¹ AHRQ CEDAR CEPI Evidence Discovery And Retrieval (2022). AHRQ. Available at: https://cds.ahrq.gov/cedar/AHRQ_CEDAR_Information_Sheet.pdf.

The following subsection provides a general overview of the repositories indexed by CEDAR. It details any changes found in the CEPI Repositories that were included in the Pilot and RI included in the Base Period effort (2020 – 2022).

3.1.1 CEPI Repositories Indexed by CEDAR

The following repositories are currently indexed by CEDAR:

- CDS Connect
- The U.S. Preventive Service Task Force (USPSTF)
- The Evidence-based Practice Centers (EPC) website
- The Effective Health Care (EHC) Program website
- The Systematic Review Data Repository™ Plus (SRDR+)

CEDAR also includes the ability to index the National Guideline Clearinghouse™ (NGC), but this is not currently enabled since the repository is offline.

Table 1 summarizes the techniques used to extract artifact lists and metadata from each repository. Indexing techniques include retrieving an extensible markup language (XML)¹² or JavaScript Object Notation (JSON)¹³ feed, scraping hypertext markup language (HTML) content, and retrieving metadata from an HTML or portable document format (PDF) document.

Table 1: CEDAR Indexing Approach for Each CEPI Repository

| Repository | XML or JSON Feed | HTML Content Scraping | HTML or PDF Metadata |
|-------------|------------------|-----------------------|----------------------|
| CDS Connect | Yes | No | No |
| USPSTF | Yes | No | Yes (tools only) |
| EPC | No | Yes | Yes |
| EHC | Yes | No | No |
| SRDR+ | Yes | No | No |

CEDAR maintains the following metadata about each artifact it indexes: (Alliant Insurance Services, 2018) (Effective Healthcare, n.d.):

- Source repository – the repository from which the artifact was imported
- Title – the title of the artifact (e.g., “Treatments for Acute Pain: A Systematic Review”)
- Description – a textual description of the artifact

¹² Extensible markup language (XML) 1.0 (fifth edition) (2008). W3C. Available at: <https://www.w3.org/TR/xml>.

¹³ The Javascript Object Notation (JSON) Data Interchange Format (2014). RFC Editor. Available at: <https://www.rfc-editor.org/rfc/rfc7159>.

- URL – the Uniform Resource Locator (URL) where the artifact can be found on the web
- Publication date – the date the artifact was published
- Status – the status of the artifact; has one of five possible values: “draft,” “active,” “archived,” “retracted,” or “unknown”
- Type – the type of the artifact (e.g., Systematic Review, Clinician Summary, Decision Aid)
- Keywords – a list of keywords assigned to the artifact by the repository
- Concepts – a list of clinical concepts assigned to the artifact by CEDAR
- DOI – the Digital Object Identifier (DOI) for the artifact, if available¹⁴
- Strength of recommendation – the strength of recommendations contained within the artifact, if available
- Quality of evidence – the quality of evidence presented by the artifact, if available
- Change history – a list of changes to the artifact with timestamps of when CEDAR found the change

Appendix E describes the source of these metadata elements for each repository.

3.1.2 Changes / Updates to CEPI Repositories

The mechanism for indexing two of the repositories changed during the base period:

- The EHC added a new XML-based list of artifacts and their metadata that replaced the earlier, fragile approach of scraping the EHC website.
- SRDR+ became available and offers a JSON-based list of artifacts and their metadata. This replaced the earlier, fragile approach of scraping the original Systematic Review Data Repository website.

3.2 Analysis of User Needs

This environmental scan considered both how users interact with health-related information from information repositories as well the kinds of users that are accessing that information. It found a clear relationship between the depth of interaction that users have with the material accessed and the kinds of user accessing the information. In turn, the types of interactions users have with the repositories drives requirements or expectations on the user interface types and the robustness of tools needed to “tune” search criteria to the level sophistication that users may expect from CEDAR.

The following summarizes themes emerging from a review of the literature and informal interviews with potential and experienced users of PCOR data detailed in Appendices B-1 and C-2.

¹⁴ DOI Foundation [Internet]. 2022. Available from: <https://www.doi.org>.

Themes and insights:

- **Clinical users of CEDAR leverage the ability to access information from both mobile and non-mobile devices and often directly from the electronic health record.**
 - Key Finding: All information within the reference implementation should be accessible from mobile devices, as well as other methods.
 - Opportunity: The CEDAR team should prioritize opportunities that present the ability to integrate CEDAR capabilities within an electronic health record (EHR) for ease of access at point of care.
- **Nonclinical users perform more complex searches.** Nonclinical users of CEDAR or clinical users engaged in research (as a part of educational efforts or the development of whitepapers) are more likely to have familiarity with structured searches, use more sophisticated search terms, and have the need to span multiple types of search criteria found in online library platforms.
 - Key Finding: APIs allow for third-party specialization of a UI and customized interfaces designed for specific use cases (e.g., for research or clinical use) to streamline access contained in CEPI sought by users.
 - Opportunity: Some users may benefit from a structured search interface that provides granular search tool options used by researchers, librarians, or other potential users. Clinical and nonclinical user groups are unlikely to be familiar with developing an API client application or an interface to integrate an API into a platform.
 - Opportunity: The creation of a “quick-start implementation” kit to integrate the CEDAR API into an environment that users are already engaged with presents opportunities for adoption by lowering the technical barriers of developing a new product against an API for nonclinical users.
- **Not all users and user groups can afford access to some of the currently available search tools.**
 - Key Finding: Tools available to researchers and clinicians may provide access to similar information (e.g., UpToDate). Some users (such as physician residents, publicly funded and smaller institutions) who rely on access to trusted information resources that are freely available or made available through their academic or nonprofit institutions may be particularly receptive to new resources to support their work. Rising costs associated with accessing clinical data (e.g., Medscape) are driving many users to seek lower-cost or free alternatives.
 - Finding: Although CEDAR indexes information from trusted and validated sources, its overall footprint is not as broad as some paid applications.
 - Opportunity: Demonstrate the value of CEDAR as a no-cost resource solution that is validated through a pilot or demonstration as an attractive alternative to other products.

- Opportunity: CEDAR’s unique combination of FAIR-based access directly to AHRQ repositories along with the no-cost use of the CEDAR RI provides powerful arguments for adoption when presented to the correct groups of users. These characteristics should be specifically called out in materials presenting CEDAR and integrated into future communications and outreach plans.
- Opportunity: Continued expansion of the resources indexed by CEDAR will enhance its appeal and value as a singular reliable source of trusted information.

3.3 Available Tools for Evidence-Based Clinical Information

Numerous tools are available to medical and other clinical staff and to researchers that provide access to evidence-based clinical guidance, and the marketplace for reliable clinical information has become saturated. These include targeted specialty information, as well as broader databases of knowledge and literature on all health conditions, such as UpToDate,¹⁵ Epocrates,¹⁶ and Medscape.¹⁷ Appendix C-2 details a sample of the top websites and applications currently available and their means of access. To meet growing user expectations for convenience and accessibility, these clinical resources are increasingly offered through a variety of means, including web pages and applications available across different devices and platforms, smartphones, or tablet computers.

Additionally, many of these resources are also integrated into major EHR systems, such as Epic and Cerner. These are sourced through the EHR’s own app stores, providing healthcare professionals with easy access to relevant information at the point of care. Appendix C-2 details a sample of the most popular apps and how they are typically accessed, either by web or mobile application. The most popular apps claim over one million downloads on both the Google and Apple stores, but they compete for users in a vibrant market. The crowded marketplace can be challenging for healthcare professionals to navigate the options and determine which resources are the most accurate and current. The market saturation has led healthcare professionals to be held responsible for evaluating the quality and credibility of these abundant options to confirm they are accessing reliable and accurate information.

3.4 Analysis of APIs

As designed, CEDAR is a service that is intended to collect, normalize, and present information from multiple data sources using a standards-based API. This service-based approach provides the flexibility for user interfaces to be designed with the needs of a specific group of users in mind. A demonstration user interface was also developed as a tool for showing the capabilities of CEDAR and to aid in testing. This user interface has evolved into a robust representation of a “generic” user interface that is tuned to meet most general needs.

¹⁵ UpToDate: Industry-leading clinical decision support. Wolters Kluwer. Available at: <https://www.wolterskluwer.com/en/solutions/uptodate>.

¹⁶ Point of Care Medical Application. Epocrates. Available at: <https://www.epocrates.com>.

¹⁷ Medscape (1994). WebMD. Available at: <https://www.medscape.com>.

The CEDAR team assessed several APIs that are designed to provide data and insights to users of clinical information (see Appendix C-2). The other API experiences are informative to the future growth of CEDAR to identify consistency in the experiences of various API development teams. These lessons from other structured API/tool/user interactions can be integrated into plans and pilot activities for CEDAR. Themes arising from review of the APIs—and experiences using them—centered around:

- The slow adoption rate of similar APIs when built exclusively as an API (lacking a competitive user interface or native tool).
- The need to proactively address ongoing API maintenance throughout its lifecycle, not solely during its active development efforts.

3.4.1 Overview of API Adoption

Also relevant for the growth and adoption of CEDAR are the behaviors and patterns of users as they relate to the use and adoption of new APIs. Because of the wealth of API implementations available, this review focused narrowly on those developed around the concepts of providing information to clinical users, with integration into tools and user interfaces provided through other development efforts.

The CEDAR team gathered the information in this section from literature reviews, insights from SMEs, feedback from users at conferences, and findings from base period pilot with AAFP. The CEDAR team also identified questions to structure the review:

1. How do APIs provide opportunity to improve scientific research?
2. Are there significant clinical or medical adoption *challenges* to highlight, when reviewing API adoption in healthcare?
3. Are there significant clinical or medical adoption *opportunities* to highlight, when reviewing API adoption in healthcare?

The CEDAR team gathered the following themes and insights from its literature review:

- **APIs provide an opportunity to improve scientific research.**
 - Key Finding: Research indicates that APIs streamline research efforts across systems and organizations, save time on data cleaning, support national and multi-site research, and improve data collection.¹⁸
 - Opportunity: The availability of an API to access AHRQ CEPI repositories could be widely attractive within the scientific research community irrespective of its immediate adoption by other users.

¹⁸Accelerating Application Programming Interfaces for Scientific Discovery: Researcher Perspectives (2021). Office of the National Coordinator for Health Information Technology. Available at: <https://www.healthit.gov/sites/default/files/page/2021-03/Accelerating-APIs-For-Scientific-Discovery-Researcher-Perspectives.pdf>.

- **Information users have privacy and security concerns that influence API adoption.**
 - Key Finding: Health systems and other health organizations are reluctant to adopt APIs because of the associated requirement to develop new process flows related to API management, maintenance, and overall governance. New system processes need to be established, in addition to implementation of the API itself, to address concerns related to privacy and security.¹⁹
 - Opportunity: CEDAR may consider working with a pilot site to discuss API management and maintenance concerns to ensure the CEDAR RI addresses privacy and security alignments in implementation.
- **Clinical and other users do not typically interact directly with APIs to find health information.**
 - Key Finding: A wide variety of CDS applications are used in clinical practice by medical and healthcare professionals, who typically access them via mobile and web apps and through applications integrated into EHR systems. These integrated apps, although presented to users as a seamless part of EHRs, use underlying API technology.
 - Key Finding: Clinicians, medical librarians, clinical researchers, and consumers use browser-based apps for non-point of care information retrieval tasks, or mobile apps for point of care patient education and management activities. Clinicians also interact commonly with these same apps in their EHRs, which vendors make available through an app library.²⁰
 - Key Finding: Currently, scientific researchers do not directly use or have total awareness of APIs, leading to low end-user adoption and implementation. This lack of experience with APIs and low-level education about API benefits generally results in researcher reluctance to promote or facilitate API implementation.²¹
 - Opportunity: Provide future users with opportunities to interact with CEDAR to demonstrate its functionality and value in users' professional settings. Additional opportunities may include the introduction of a mobile application version of CEDAR, which could accelerate its adoption through enhanced functionality across multiple user environments.

¹⁹Accelerating Application Programming Interfaces for Scientific Discovery: Provider Perspectives (2022). Office of the National Coordinator for Health Information Technology. Available at: https://www.healthit.gov/sites/default/files/page/2022-08/Accelerating_APIs_Provider_Perspective.pdf.

²⁰At recent count, Epic's App Orchard offered as many as 450 standards-based APIs and is cited as one of the largest FHIR API portfolios provided by an EHR vendor. Fierce Healthcare; 2022 [cited 2022 Mar 25]. Available from: <https://www.fiercehealthcare.com/health-tech/epic-plans-overhaul-its-app-market-opens-new-connection-hub-developers-here-are-key>

²¹Accelerating Application Programming Interfaces for Scientific Discovery: Researcher Perspectives (2021). Office of the National Coordinator for Health Information Technology. Available at: <https://www.healthit.gov/sites/default/files/page/2021-03/Accelerating-APIs-For-Scientific-Discovery-Researcher-Perspectives.pdf>.

- **The health field is becoming saturated with health apps designed for web and mobile use.**
 - Key Finding: Existing literature posits that current health community members prefer using mobile apps because they allow easy access to data and information. The extensive volume of health-focused web apps seen across mobile platforms signals that developers aim to support this preference.²² Contrarily, APIs as standalone tools are complicated for lay people to understand and implement in clinical practice.²³
 - Key Finding: The past 10 years have seen widespread adoption of mobile platforms and apps that provide point of care access to evidence-based, best-practice clinical guidelines to users, particularly by physicians and medical students, via mobile phones and tablets. See Appendix C.2 for a list of popular mobile apps in the health field. The CEDAR team has not found evidence, however, to show that physicians and medical students themselves are developing apps that interact with APIs for this use.
 - Opportunity: Determine CEDAR’s unique value in the health web app space and explore prioritization of potential developers to target for new app development or enhancement of existing apps that can integrate AHRQ CEPI findings. CEDAR has started this strategic analysis; see Tables 5 and 6 for an initial list of primary web apps used by clinical and scientific research audiences.

A search for clinical decision support tools on the Apple App Store and the Google Play App Store reveals only a dozen or so applications available, and it demonstrates that a limited range of these healthcare products are marketed through these sources to the clinician or practice. Instead, the environmental scan shows that companies seeking to expose their apps to clinicians for adoption have targeted EHR vendors. Major EHR systems have made access to hundreds of apps leveraging API technology easy to find through their app stores, such as the Epic Orchard.²⁴ This differentiation between commonly available and specialized app stores influences where health providers find resources to integrate information into their health record system, and CEDAR should consider how to maximize its positioning to drive future adoption.

3.4.2 API Maintenance

At the other end of the API development life cycle (adoption, proliferation, use, sustainment/maintenance, and sunset/closeout), API maintenance is an aspect of development that is often not considered until much later. Early consideration of maintenance needs is key to the successful planning, implementation, and maturation of an API. The CEDAR team developed and documented an approach to versioning of the API to minimize the impact of

²² Grundy, Q. (2022) “A review of the quality and impact of Mobile Health Apps,” Annual Review of Public Health, 43(1), pp. 117–134. Available at: <https://doi.org/10.1146/annurev-publhealth-052020-103738>.

²³ Accelerating Application Programming Interfaces for Scientific Discovery: Researcher Perspectives (2021). Office of the National Coordinator for Health Information Technology. Available at: <https://www.healthit.gov/sites/default/files/page/2021-03/Accelerating-APIs-For-Scientific-Discovery-Researcher-Perspectives.pdf>.

²⁴ Home - Vendor Services (2019). Epic. Available at: <https://vendorservices.epic.com/>.

changes to the existing users of the API while allowing for future enhancements.²⁵ The CEDAR Pilot, although focused primarily on development and implementation activities,²⁵ must also consider maintenance in decisions that will impact all parts of the lifecycle.

Maintaining digital tool sets such as APIs requires organizational infrastructure and staff. This can be perceived as a burden to some organizations and entities, especially when they operate on low budgets and have many competing technical priorities. This section reviews some of the elements that CEDAR needs to sustain and manage future growth:

- **API source information repository maintenance.** Maintaining a GitHub repository that contains open-source community contributions to solve specific clinical information retrieval tasks using the CEDAR API requires an ongoing commitment by an organization to supply technical expertise and other resources.
- **Effective search mapping requires complex mapping of terms and clinical concepts.** The National Library of Medicine’s (NLM’s) Unified Medical Language System (UMLS) defines more than four million semantic primitives—language-independent unique clinical concepts. However, mapping of the content of the data resources accessible via the CEDAR API to UMLS semantic primitives yields less than 3,000 semantic primitives indexed by and accessible with the CEDAR API. This limited mapping of semantic primitives means that the entry by a clinician of a randomly chosen clinical search term into the CEDAR API is unlikely to return any result. Instead, the lack of returns is likely to lead to a perception by the clinician that the CEDAR API offers no value—a perception that could lead to rapid spread throughout the clinician community.
- **APIs require maintenance to maintain seamless integration with data sources (repositories).** Changes to the APIs to the data repositories accessed by the CEDAR API will require ongoing maintenance of the CEDAR RI.
- **Ongoing maintenance of website, links, and landing pages.** Placing links to the CEDAR landing page on other agencies’ websites (e.g., the NLM or National Science Foundation [NSF]) will require ongoing communication and collaboration.
- **Evolving and advancing the capabilities of the API and the demonstration interface will continue to require technical resources throughout the life of the tool.** As novel advances in user interface design occur that minimize the cognitive effort required to retrieve the desired information via the CEDAR API, technical resources will be required to integrate those advances in user interface design into any future CEDAR UI.
- **Continual outreach and engagement with end users can identify and help prioritize API gaps and adoption opportunities to remain relevant.** Targeted outreach to specific end users (through academic centers, teaching hospitals, associated professional organizations, and through national, regional, and local clinical society meetings) can attract new API interest and reinforce long-term planning to retain CEDAR value and drive adoption. As many clinical and scientific community members have shown low awareness of how APIs can support their practice and research, a well-constructed

²⁵ CEDAR API Versioning Approach delivered Nov 2021.

outreach plan can educate users and support and inform technical advancements to the CEDAR RI and potentially to its underlying data repositories.

3.4.3 Functionality Among Tools and Resources

The previous sections analyzed the type of information available for CEDAR to index (Section 3.1), competitors to CEDAR (Sections 3.3 and 3.4), and a better understanding of the professional groups that use CEDAR information (Section 3.2). This section identifies some common themes that can be seen looking across the flow of information from other tools and implementations.

As depicted by Figure 2, information flows from users to the tools and then repositories or other resources as they enter criteria for searches. Information in the form of results flows back to the user from the repository in the form of results or responses to those queries. This flow is facilitated by the program-to-program interface (the API) and presented through the UI of the tool (application or web browser). The assessment of associations between these elements applies directly to CEDAR and pilot planning.

Functionally, the end user does not interact directly with an API. This disconnect contributes to the difficulty in raising awareness across multiple communities and stakeholders of the benefits that a new API can provide. Users value the quality and quantity of information accessed through a tool based how it is provided to them.²⁶

AHRQ developed CEDAR to make CEPI resources adhere to FAIR principles—features not evident to end users until a UI delivers the indexed data. Repositories can meet FAIR principles, but until the UI exists to allow users access to the data, the user community will not benefit from the effort. Additional education and outreach, differentiated to meet specific user informational needs within their professional context and experiences, can expand interest in CEDAR as a technical product, while at the same time reinforcing the value of the information CEDAR curates.

To access CEDAR and make the best use of the API, academia and medical institutions or other third-party vendors will need to create their own UI. A pilot effort could demonstrate practical applications of CEDAR to bring awareness to its functionality. Future analyses can also assess how CEDAR's adherence to FAIR principles impacts future and ongoing adoption.²⁷

Based on their current practices and exposure to technical architectures, varying users also have initial expectations about the type of tool (platform) that they reliably use as a resource when connecting to information repositories. Tools with no presence on their preferred platform are

²⁶ RedHat (2019) What is API design? <https://www.redhat.com/en/topics/api/what-is-api-design>; Garg, D. (2022) Bing's Approach to Search Engine Design: 10 Principles. UX Planet, <https://uxplanet.org/bings-approach-to-search-engine-design-10-principles-9962c657d2a0>; Pratama, M A T and Cahyadi, M A T Effect of User Interface and User Experience on Application Sales 2020 IOP Conf. Ser.: Mater. Sci. Eng. 879 012133

²⁷ Paton C, Kushniruk A, Borycki E, English M, Warren J. Improving the Usability and Safety of Digital Health Systems: The Role of Predictive Human-Computer Interaction Modeling. J Med Internet Res 2021;23(5):e25281. URL: <https://www.jmir.org/2021/5/e25281>

typically not considered, regardless of the quality of information that they provide.²⁸ To fully reach user groups and increase CEDAR use by multiple user audiences, CEDAR has an opportunity to become equally accessible across mobile and laptop platforms to match current user preferences.²⁹

Development and dissemination of toolkits to support UIs that can be tuned to meet the specific needs of a user group could be considered “step one” toward broader CEDAR adoption. Making these toolkits available to technical developers provides a jumpstart to aid end users by simplifying access to development tools for groups or individuals with at least a limited exposure to APIs, as well as to organizations’ IT shops looking for lightweight, low- to no-cost implementation efforts. Along with the CEDAR RI, toolkits will increase public awareness about the API and accentuate functionality for users. In this way, CEDAR toolkits can further reduce perceived barriers or hesitation based on unfamiliarity and help to integrate CEDAR into existing systems. Paired with educational outreach, AHRQ can monitor toolkit adoption to determine the best methods to meet multiple user needs and build appropriate CEDAR advancements for continued user appeal over time.

Finally, users may initially select a tool based on an expectation of the information availability from a specific source. For example, a user may choose to use CEDAR because they know that it indexes information from specific AHRQ repositories such as SRDR+. There is a direct relation between the tools that users choose to use and the repositories that they are using. A key method to identify potential users for CEDAR will be targeting existing users of the repositories indexed by CEDAR.

²⁸ D. Sharma, R. Shukla, A. K. Giri and S. Kumar, "A Brief Review on Search Engine Optimization," 2019 9th International Conference on Cloud Computing, Data Science & Engineering (Confluence), Noida, India, 2019, pp. 687-692, doi: 10.1109/CONFLUENCE.2019.8776976.

²⁹ RedHat (2019) What is API design? <https://www.redhat.com/en/topics/api/what-is-api-design>.

4 Identification of Risks

4.1 Technical Risks

CEDAR was designed as a service built with a standards-based API that collects and presents information from multiple data sources. This provides the flexibility for user interfaces to be designed with the needs of a specific group of users in mind, separating the development effort of the interface from the development of the data repository indexing service.

This section captures information areas where the reference implementation of CEDAR is reliant on external technologies, information availability, or other factors beyond the control and scope of the product team. These items may present risk to the success or widespread use of the CEDAR API.

4.1.1 Citation Resource Maturity

The FHIR Citation resource is currently at a low level of maturity—FHIR Maturity 0 (FMM0)³⁰—and lacks strong FHIR community support.³¹ This means that the Citation resource is currently published in FHIR (revision 5) as draft and is waiting for FHIR Management Group (FMG) approval. Specifically, the FMG is *“presently considering whether this resource is appropriate to include in the FHIR specification”* and has *“provisionally approved the Citation Resource with the qualification that we will continue to evaluate its appropriateness as it develops in the community.”*

Only two development projects—COVID-19 Knowledge Accelerator (COKA) and CEDAR—are currently using the Citation resource, though others, including SRDR+, have expressed interest. Lack of strong community participation may result in the Citation resource not supporting all the potential use cases, which could further discourage adoption.

Significant changes to the FHIR Citation resource or its removal from the FHIR specification would likely require updates to CEDAR software code and to any clients of CEDAR.

4.1.2 Indexer Stability

CEDAR relies upon certain features of each CEPI repository to perform indexing of the artifacts hosted in each repository. Changes to repository structure or format could break existing approaches to indexing and require updates to CEDAR software code. Appendix F lists the features of each repository that CEDAR relies upon and identifies changes to those repositories that would require CEDAR updates.

4.2 Other Risks

The primary objective for this updated ES23 document was to serve as a follow-on review of issues evaluated in the 2020 environmental scan. In conducting this review, the MITRE team reevaluated CEDAR technical specifications of indexed repositories to identify factors that could limit or expedite continued technical integration of the CEDAR RI and its future growth. MITRE

³⁰Version Management Policy - Maturity Levels (2023). HL7.org. Available at: <http://build.fhir.org/versions.html>.

³¹Citation Resource – Content (2023). HL7.org. Available at: <https://build.fhir.org/citation.html>.

also noted that additional risks may influence CEDAR’s long-term success. Two risks are described below: user engagement and limited indexed content. Other risks may also affect CEDAR adoption and implementation but were not within the scope of this environmental scan to identify for mitigation. Other factors relevant to the CEDAR RI’s continued development and evolution, which may be internal to AHRQ or external and related to users’ circumstances, also raise potential challenges for CEDAR long-term success.

4.2.1 User Engagement

Consistent and broad user engagement is needed to ensure that the reference implementation evolves in ways that are best aligned with users’ existing and emergent needs. Additionally, engagement with users and potential users during development processes increases the likelihood of long-term adoption and use of the tool, and realization of the goals that CEDAR provides improved access to AHRQ PCOR information. Improved access may be described as one of the following:

- Faster access to existing materials through a single interface, used to access several repositories with a single search.
- Searching and providing access to materials that otherwise would have been overlooked or excluded from search parameters.

Timing and other constraints limited the ability for this AHRQ CEPI project to engage directly with potential CEDAR users. Regular, proliferated, direct engagement with the array of clinical, scientific, and technical users whose work can benefit from access to data that CEDAR provides can support CEDAR evolution in a direction consistent with their needs.

4.2.2 Limited Indexed Content

The information indexed by CEDAR is currently limited to information found in CEPI repositories. This represents highly reliable and quality PCOR information; nevertheless, the overall quantity of information returned from a search is constrained by the amount information in those repositories. CEDAR “competes” in a product space where indexed information sets are very broad and provide higher quantities of responses in return to executed searches.

5 Conclusions and Recommendations

Currently, CEDAR has no direct competitor—that is, a single API or user interface that provides direct access to the PCOR information AHRQ provides. However, clinicians have many choices to access health data information to address clinical questions. These tools include applications, mobile and desktop platform interfaces, websites with robust access to commercial and specialty sets of information, as well as some specialty APIs that have a more significantly established user base, and in most cases also a broad focus of information being targeted. Overall, there is no “one stop shop,” and many of the tools require paid access or subscriptions to have the most current or complete access to content. Clinicians have a wealth of information sources—perhaps too many—to effectively and consistently meet all their access to information needs in the most efficient, consistent, and timely manner.

Due to the fractured nature of the product and information space that CEDAR sits within, CEDAR faces many challenges for directly attracting and maintaining users of either the API or the user interface. CEDAR currently indexes a very limited set of data from the source repositories maintained by CEPI. CEDAR users are likely those that are already familiar with the information AHRQ provides and makes available today. Expanding the user base and raising user awareness may be addressed through a combination of tools, awareness, and outreach efforts, as well as the addition of new sources of information indexed by CEDAR as a part of the pilot or future development efforts. One of the most unique and compelling aspects of CEDAR is its nature as a tool that provides integrated access to AHRQ CEPI resources without any cost to the user.

Several recommendations are applicable for the short-term development plans for CEDAR and should be considered in the context of the scope and development for the 2023 Pilot. Some of these have been developed through this environmental scan, as well as some of the recommendations that were developed for ES20 that have yet to be fully addressed. Other sources of recommendations include the current state of the API and RI and findings from the pilot activities conducted in 2022.

Based on these findings, this analysis, and the review of the identified risks, the following near-term and long-term recommendations are provided:

5.1 Near-Term Recommendations

- **Augment FAIR assessment and the C-FAIR tool with the inclusion of the TRUST assessment.** To enhance the FAIR assessment of CEDAR, consider expanding it to include an assessment of TRUST.
- **Target users and use cases.** To optimize results of the 2023 Pilot, focus on a specific set of users and associated use cases to maximize the benefit of CEDAR for that subset of needs. Correct identification of the largest segment of users and associated use cases or needs will be key to driving adoption of CEDAR.
- **Establish enhancement priorities for CEDAR.** Prioritize goals for CEDAR development and expansion based on uses cases and target user groups. Continue to seek understanding of different needs and pain points associated with the current use of CEPI repositories and web-based data repositories in general to enhance the capabilities of the

CEDAR RI. This may include features and capabilities of the API that are tailored to meet these needs of those groups, as well as drive decisions regarding CEDAR expansion to index additional information from additional AHRQ repositories.

- **Differentiate CEDAR from other evidence-based resources available to clinicians and researchers.** Quantify the key differences and unique qualities that separate CEDAR from other tools which can be used to access PCOR information.
 - Emphasize the high-quality and high-reliability nature of the information indexed by CEDAR to include C-FAIR assessment information and government information sources, and to provide a public good for all audiences.
 - CEDAR is a free tool that clinicians and researchers can access without a license or subscription cost. Equivalent options offering access to a similar level of trustworthy data are only offered through fee-based services.
- **Develop a quick implementation kit for CEDAR.** Develop a toolkit for the quick and easy integration of the CEDAR API into a user environment.
 - Consider user interface options that allow users to sample the CEDAR data sets through a trial app, or equivalent.

5.2 Long-Term Recommendations

Other items may take a longer effort to realize; these include strategic goals and direction for the long-term success of CEDAR. As with the near-term recommendations there are a variety of sources for these. Addressing these recommendations may start in the 2023 Pilot or the RI, but full resolution of these strategic recommendations is unlikely within the current scope of the CEDAR development effort. Any remaining items after the completion of RI updates should be reassessed and considered as a part of the strategic roadmap for CEDAR.

- **Broaden the information accessible through CEDAR.** Extend support for indexing beyond the indexed CEPI repositories and beyond PCOR information sets to consider including broader health information resources that are also of interest to clinicians.
- **Identify challenges or limitations with current search capabilities built into to the repository's native search features (i.e., the Effective Health Care Program “Search EHC” search tool).**³² Work with repository owners to assess interest in the use of the CEDAR RI or API capabilities as a replacement for their own search functions for their direct users.
- **Engage in industry working groups on TRUST.** Recognizing a growing interest in the trustworthiness of data and its origins, include a formal commitment to evaluating CEDAR’s trustworthiness with an augmented C-FAIR tool that includes TRUST principles.

³² Evidence-based Practice Centers (2017) Effective Health Care (EHC) Program. Available at: <https://effectivehealthcare.ahrq.gov/about/epc>.

Appendix A FAIR White Paper and Tool Assessments

The CEDAR team leveraged the C-FAIR Tool to complete four assessments that measured the FAIR alignment of the CEPI repositories and the CEDAR API. Results from the assessments are included in the CEDAR Final Report 2022³³ and will be submitted to the *Learning Health Systems* journal for publication.

Additional FAIR assessments will be completed during the option period, and results will inform the evolution of the API, RI, and the upcoming Pilot.

A.1 Summarizing the Tools Available for Measuring Alignment With FAIR

The purpose of evaluating a tool such as CEDAR for FAIR data principles is to ensure the quality and reliability of the results it returns, and to identify opportunities to improve these results. ES20 provided an overview of the FAIR principles established by Force11 that “allow both machines and humans to find, access, interoperate, and re-use research data”³⁴ These standards align with the AHRQ goal of increasing the availability of data for use by clinicians, patients, and others.³⁵ ES20 found that existing FAIR assessment tools provided limited insight into health data repositories but not the full repositories, which CEDAR is designed to index. To address this gap, the CEDAR FAIR (C-FAIR) Tool was developed to specifically evaluate the AHRQ CEPI repositories.

A.2 Augmenting FAIR Data Principles With TRUST Principles

The FAIR domain for digital artifacts is dynamic and requires attention to preserving trustworthy digital repositories (TDR) for clinicians and researchers. Users of CEDAR must be able to have confidence in the accuracy, integrity, and authenticity of evidence returned during a search of AHRQ repositories.

FAIR data principles provide the user with assurance that the digital artifacts being accessed are of high quality and reliable at that point in time. A data repository, however, must also provide assurances about the quality and preservation of information over a period of time, requiring the consideration of additional elements. To supplement FAIR principles and provide evidence of best practices in data stewardship, Dr. Dawei Lin, PhD (Division of Allergy, Immunology, and Transplantation, NIAID, NIH), and the members of the Research Data Alliance ([RDA](#)) and World Data System ([WDS](#))³⁶ recommend augmenting FAIR principles with Transparency,

³³ Agency for Healthcare Research and Quality. “CEPI Evidence Discovery And Retrieval (CEDAR) Project.” <https://digital.ahrq.gov/ahrq-funded-projects/cepi-evidence-discovery-and-retrieval-cedar-project>

³⁴ 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.

³⁵ Agency for Healthcare Research and Quality. “CEPI Evidence Discovery And Retrieval (CEDAR) Project.” <https://digital.ahrq.gov/ahrq-funded-projects/cepi-evidence-discovery-and-retrieval-cedar-project>

³⁶ “The TRUST Principles for Digital Repositories” Published in Scientific Data | Data Science at NIH.

Responsibility, User focus, Sustainability, and Technology (TRUST)³⁷ principles. TRUST is a set of guiding principles that complement FAIR.³⁸ These principles provide a common framework to facilitate discussion and improve public trust of digital artifacts.³⁹

The development of TRUST in data repositories aligns with new goals for the Department of Health and Human Services (HHS). In 2022, HHS identified “the restoration of trust and accelerating advancements in science and research” as a key strategic goal. (Goal #4 2022-26)⁴⁰ Strategic Objective 4.4 specifically aims to “Improve data collection, use, and evaluation to increase evidence-based knowledge that leads to better health outcomes...”⁴¹ The goal aids in reducing health disparities, and improving social well-being, equity, and economic resilience. Goal #5 of the HHS 2022-2026 strategic plan focuses on advancing strategic management to build trust, transparency, and accountability.

TRUST is different from the word “trust.” TRUST is the idea that a researcher/clinician can be confident the system is returning appropriate and complete results. Trust in data has traditionally been a byproduct of the practices employed by data stewards.⁴² Some believe that use of FAIR principles brings transparency to data stewardship that engenders greater trust, and that more use of the principles “can strengthen data sharing and move toward the harmonization of data from heterogenous silos.”⁴³ In order to achieve this goal, the TRUST of a data repository must also be considered in the same fashion as the consideration for the alignment with FAIR of the information being accessed.

To align with the HHS goals, advance the FAIR data principles, and foster greater public trust in AHRQ repositories, the CEDAR API could be enhanced by continuing to incorporate the new TRUST principles in future assessments.

A.3 Evaluating Trustworthiness

Using the TRUST principles as a framework, the CEDAR team identified the following three questions to address as AHRQ incorporates trustworthiness as a component of CEDAR and the CEDAR API:

1. How is “trustworthiness” defined in the context of searches conducted of the CEPI repositories by the CEDAR API?
2. How can “trustworthiness” be measured?
3. Does existing literature answer and/or support either of the above questions?

³⁷ Lin, D., Crabtree, J., Dillo, I. et al. The TRUST Principles for digital repositories. *Sci Data* 7, 144 (2020). <https://doi.org/10.1038/s41597-020-0486-7>.

³⁸ Ibid.

³⁹ Ibid.

⁴⁰ Strategic Goal 4: Restore Trust and Accelerate Advancements in Science and Research for All. <https://www.hhs.gov/about/strategic-plan/2022-2026/goal-4/index.html>

⁴¹ HHS Strategic Goal 4.4. <https://www.hhs.gov/about/strategic-plan/2022-2026/goal-4/objective-4-4/index.html>

⁴² See Lin, D., Crabtree, J., Dillo, I. et al.³³

⁴³ Inau E, Sack J, Waltemath D, Zeleke A. Initiatives, Concepts, and Implementation Practices of FAIR (Findable, Accessible, Interoperable, and Reusable) Data Principles in Health Data Stewardship Practice: Protocol for a Scoping Review. *JMIR Res Protoc* 2021;10(2):e22505. <https://www.researchprotocols.org/2021/2/e22505>

To explore trustworthiness within CEDAR, the team conducted a literature search to identify the frequency and context of trust in health digital artifacts. Key word strings searched included:

- (“trustworthiness” OR “trust”) AND (“clinical decision support” OR “CDS”)
- “assess” AND (“trustworthiness” OR “trust”) AND (“clinical decision support” OR “CDS”)
- (“build” OR “maintain” OR “assess”) AND (“trustworthiness” OR “trust”) AND (“clinical decision support” OR “CDS”)
- "PCOR" AND (“trustworthiness” OR “trust”) AND (“clinical decision support” OR “CDS”)
- "PCOR" AND (“trustworthiness” OR “trust”) AND (“health”)

Databases explored included: Google Scholar, PubMed, AAMC, NEJM, JAMIA over a 5-year lookback period between 2019 and 2022. The search findings are summarized in the following table.

Table 2: Sample List of Assessment Tools for Trustworthiness

| Assessment Tool | Function | Benefits | Limitations |
|---|---|--|---|
| Data Stewardship Maturity Matrix ^{44 45} | Addresses trustworthiness of the individual data set level. | Establishes minimum bar for stewardship practices to manage widely differing data types across various repositories. Applies standards that meet U.S. Federal regulations. Automated tool can be integrated into workflows. Can be used for self-assessment. Free self-evaluation tool, developed for U.S. agency. | Developed specifically for National Oceanic and Atmospheric Administration (NOAA). Not actively updated and may not transfer easily to other agencies. |
| FAIR Guiding Principles ⁴⁶ | Detail guidelines for electronic tools to be findable, accessible, interoperable, and reusable. | CEDAR is already aligned to aspects of the FAIR Guiding Principles for other facets. | Does not assess trustworthiness. |

⁴⁴ Peng, G., PhD. Data Stewardship Maturity Matrix (DSMM) Introduction and Application. Library of Congress Annual Digital Preservation – DSA Meeting. September 18-19, 2017. https://www.digitalpreservation.gov/meetings/DSA2017/Day_1/10_CP_Part_1_GePeng_NOAA.pdf

⁴⁵ Peng, G., Privette, J. L., Kearns, E. J., Ritchey, N. A. & Ansari, S. A unified framework for measuring stewardship practices applied to digital environmental datasets. *Data Sci J* 13 (2015).

⁴⁶FAIR Principles (2022). Go FAIR. Available at: <https://www.go-fair.org/fair-principles>.

| Assessment Tool | Function | Benefits | Limitations |
|--|--|--|---|
| CoreTrustSeal Trustworthy Data Repositories Requirements (CTDRR) ⁴⁷ | <p>Well-established tool to assess and certify data repositories that meet the 16 core criteria defined by CoreTrustSeal.</p> <p>Established by an international community based non-governmental and non-profit participants.</p> | <p>Provides independent, third-party verification of trustworthiness of a data repository.</p> <p>Adheres to standards that model FAIR data principles.</p> <p>Used internationally for large data repositories.</p> <p>Provides best practice model for data stewardship.</p> | <p>2-yr certification process; fee-based.</p> <p>CTDRR may necessitate repository stewards complete a CTDRR review of their respective repositories for CEDAR to be considered for CoreTrustSeal certification.</p> |
| The TRUST Principles for digital repositories ⁴⁸ | <p>Offers a common framework of principles with which to align that can be used for evaluation of repositories.</p> <p>Developed by members of the CoreTrustSeal Standards and Certification Board.</p> <p>Promotes model of FAIR for data objects and TRUST for data repositories.⁴⁹</p> | <p>Generalizes trustworthiness beyond disciplinary data repositories.</p> <p>Works in concert with other principles such as FAIR Guiding Principles.</p> <p>Easy to understand.</p> | <p>Still in development (initiated in 2020), not widely adopted.</p> |

⁴⁷CoreTrustSeal (2023). CoreTrustSeal. Available at: <https://www.coretrustseal.org>.

⁴⁸Articulated through community consensus, the TRUST Principles are an endorsed set of guiding principles to demonstrate digital repository trustworthiness. Transparency, Responsibility, User focus, Sustainability, and Technology: The Trust Principles provide a common framework to facilitate discussion and implementation of best practice in digital preservation by all stakeholders. Available at: https://www.rd-alliance.org/system/files/documents/TRUST_RDA_IG_2019_0.pdf.

⁴⁹Lin, D., Crabtree, J., Dillo, I. *et al.* The TRUST Principles for digital repositories. *Sci Data* 7, 144 (2020). <https://doi.org/10.1038/s41597-020-0486-7>.

Table 3: Sample of Search Results for “Trust”

| Databases Explored | “Trust” AND “Clinical Decision Support” | “Trust” AND “Clinical Decision Support” AND “Health” | “Trust” AND “PCOR” AND “Clinical Decision Support” | “Trust” AND “PCOR” AND “Health” |
|---------------------------|--|---|---|--|
| Google Scholar | 13,200 articles | 5,810 articles | 36 articles | 53 articles |
| PubMed | 2,543 | 13 | 11,630 | 13 |
| NEJM | 525 | 459 | 0 | 0 |
| JAMIA | 588 | 0 | 6 | 7 |

Themes from the CEDAR team’s research show that:

- Trust is a frequently cited term generally in medical literature but is found in limited to moderate amounts in connection with clinical decision support.
- Trust is cited in particular for clinicians often in relationship to machine learning tools, AI, or predictive capabilities. Trust is commonly cited for patients participating in research trials, in the healthcare setting, and in the context of using a wide variety of health tools.
- Trust is frequently cited in studies of clinical decision support tools that are dependent on artificial intelligence, machine learning, or natural language processing techniques.

Appendix B Industry Insights

This appendix captures lessons learned and themes from the AAFP pilot, as well as insights from conversations with health IT experts.

B.1 Lessons from the 2022 Pilot

Lessons learned from the 2022 pilot of CEDAR with AAFP has been divided into developer and end-user feedback.

Developer:

- Reported that the CEDAR API documentation was sufficient; additional information on the FHIR Standard was useful for a developer who was unfamiliar with FHIR.
- Reported that developing a successful CEDAR application required a relatively low level of effort and resources.

End Users:

- Reported that the CEDAR Search application was easy to understand.
- Reported that they needed very limited training and documentation to successfully navigate the platform.
- Reported that evidence from CEPI repositories may be useful for gathering information before or after a clinical encounter. Reasons for this include the type of evidence AHRQ repositories offer and when the evidence is updated.
- Reported trusting that returned results came from reputable resources, despite not being aware of all the CEPI resources and repositories indexed by CEDAR.
- Reported receiving unexpected results and results that did not address what the pilot participant was searching for.
- Reported that using CEDAR increased participant knowledge of different CEPI repositories and resources.

In addition to the feedback provided, some key opportunities have been identified for future enhancement by both groups:

- Include a description of indexed repositories in CEDAR.
- Expand implementation of CEDAR to further the awareness and FAIR of information maintained by CEPI.

B.2 Feedback from Health IT Experts

The CEDAR team has also used informal interviews to obtain qualitative data from AMIA conference participants and health IT leaders, both within and external to MITRE. The following bullets capture themes around the positioning of CEDAR as a tool and generalized expectations for the sharing of clinical information in a timely fashion through web-based information resources.

- **Incorporate search tools into existing online research platforms.**
 - Key Finding: A health sciences librarian at AMIA recommended incorporating the CEDAR API into the online research platforms that are already in use by health sciences libraries such as [EBSCO](#) or any of the [popular databases](#) and imbedded tools like PubMed/MEDLINE, Web of Science, and UpToDate. Another health sciences librarian recommended partnering with resources that are behind a paywall to allow for additional visibility by students, clinicians, and researchers who already have their “go-to” resources.
 - Opportunity: UpToDate already links to references; it could potentially include a link to CEDAR or pull from CEDAR’s repositories if the API were built into the tool.
- **End users seek a user interface, not an API.**
 - Key Finding: Providing an open-source API is insufficient to meet end users’ needs for information access. Potential users of CEDAR are often not the in the same part of an organization as the developers that are needed to build a search tool against the CEDAR API. AMIA audience members asked about the demo user interface and where it exists on the AHRQ or CDS Connect website. End users of the PCOR information provided by CEDAR are clinicians and researchers, not API or software developers.
Opportunity: A user interface should be available so end users can use CEDAR before deciding whether to build their own user interface using the programming resources available on the site (i.e., the API).
- **End users seek a mobile application or mobile-friendly access.**
 - Key Finding: Anecdotal evidence is consistent with published findings that clinicians prefer tools be incorporated directly in the EMR, but for convenience will reference mobile devices for supplemental information.
 - Opportunity: There is interest in widgets or applets that can be easily dropped onto existing sites with a “plug and play” level of ease.
- **CEDAR could improve health data using FHIR.**
 - Key Finding: AMIA conference attendees discussed the possibility of the API being built using HL7 FHIR and application to health data in EHRs. The API could be integrated to allow input in the patient record to link to resources related to a patient’s past medical history, diagnosis, labs, and/or guidelines specific to their age and gender (i.e., cancer screening).
 - Opportunity: The API could allow for input into the patient record that links to resources related to patient history, diagnosis, labs, and relevant guidelines.

At the 2022 AMIA Symposium, the CEDAR team presented an overview of the pilot project from the perspectives of AHRQ, the engineering team at MITRE, and the American Academy of Family Physicians, which piloted the CEDAR prototype. Generalizable approaches to harmonizing metadata, using standards, and incorporating CEDAR output into products aimed at improving clinical decision making were presented. The pilot portion of the presentation included a review of the pilot results and commentary on the experience of partnering to create a bespoke UI for their website. The results included comments from end users about the limited number of artifacts returned in searches. Users also posed questions about the utility of CEDAR, yet praised the ease of use and speed in which it returned search results.

Appendix C Resources Researched

C.1 Other Health Information Repositories

As a part of ES20, the CEDAR team conducted an assessment to identify available resources and sources of PCOR information, as well as a broader set of “patient-centered and other health-related resources that provide information for patients and clinicians who are engaged in making decisions related to healthcare plans and treatment.” The previous assessment (captured in Appendix B of ES20) was conducted partly to consider potential elements of overlap or integration possibilities for CEDAR, as well as to better understand the alternative resources that exist for the users of that information.

Since that time, few changes were made to the overall landscape of available information. Table 4 provides a listing of those new repositories, with direct access via APIs, that have been identified since the survey of available information. It also provides a listing of those repositories that were included in the initial scan that are no longer assessable or are offline.

Table 4: Changes to Available Repositories of Health-Related Data

| Repository Name | Free / Open Access | Description | Considerations for CEDAR | Specific PCOR Focus | Timeliness |
|--|--------------------|---|--------------------------------|---------------------|----------------|
| UPDATED: GradePro Database of GRADE EtDs and Guidelines ⁵⁰ | Yes | Searchable database of guidelines (login required) | Depends on ease of integration | Medium | Unclear |
| REMOVED: JBI Systematic Review Register ⁵¹ | n/a | <i>Removed</i> – International register of ongoing systematic reviews | <i>Removed</i> | <i>Removed</i> | <i>Removed</i> |
| NEW: Research Portfolio Online Reporting Tools (RePORT) Expenditures and Results (RePORTER) ⁵² | Yes | “Repository of NIH-funded research projects and access publications and patents resulting from NIH funding” ⁵³ | Unclear | Low | Yes |
| NEW: Bookshelf ⁵⁴ | Yes | For systematic reviews – “Bookshelf provides free online access to books and documents in life science and healthcare.” ⁵⁵ | Unclear | Low | Yes |

⁵⁰ AI in Evidence-Based Healthcare Group (2021). GRADEpro GDT. Available at: <https://www.gradepro.org>.

⁵¹ Joanna Briggs. Available at: <https://joannabriggs.org>.

⁵² RePORT Research Portfolio Online Reporting Tools. National Institutes of Health. Available at: <https://report.nih.gov>.

⁵³ Ibid.

⁵⁴ Bookshelf. National Library of Medicine - National Center for Biotechnology Information. Available at: <https://www.ncbi.nlm.nih.gov/books>.

⁵⁵ Ibid.

C.2 Popular Health Information Tools

Medical professionals, researchers, and medical students benefit from a wide range of tools and electronic resources with which to conduct their research or obtain insights for clinical decision support. Many of these are narrowly focused on specific subjects and do not source specifically from PCOR repositories. Tables 5 and 6 detail popular resources⁵⁶ and examples of additional specialized apps frequently downloaded for clinical point of care and research.

Table 5: Most-Popular Sources of Information Available to Clinicians

| Resource | Cost | App or Web resource | Focused information retrieval topics |
|-----------------|-------------|----------------------------|---|
| Epocrates | Freemium | App | Drugs, diagnostic & treatment guidelines, ID mgmt., clinical calculators, CME |
| Medscape | Freemium | App/web | Drugs, diagnostic & treatment guidelines, ID mgmt., clinical calculators, CME, procedures |
| UpToDate | Paid | App/web | Drugs, diagnostic & treatment guidelines, ID mgmt., clinical calculators, CME |
| PubMed | Free | App | MeSH-based search of MEDLINE and PubMedCentral |
| Hospitalist | Free | App | DDx diagnostic & treatment guidelines |
| MD Calc | Free | App | Disease risk, metabolic status calculators |
| USPSTF | Free | App/web | Primary care disease screening, counseling, and preventive medication guidelines |
| Touch Surgery | Free | App/web | Surgical procedures |
| Covidence | Paid | Web | Resource and tool to streamline systematic reviews |

Table 6: Other Sources of Information Available to Clinicians

| Resource | Cost | App or Web resource | Focused information retrieval topics |
|--------------------------|-------------|----------------------------|---|
| BMJ Best Practice | Paid | Web | Drugs, diagnostic & treatment guidelines, ID mgmt., Clinical decision support |
| Clinical Problem Solvers | Paid | App | Diagnosis support |
| DynaMed | Freemium | App | Drugs, diagnostic & treatment guidelines, ID management, CME, procedures |
| Evernote | Paid | App | Clinical note taking |

⁵⁶ Apps designated as popular have received over 1 million downloads from the Google and/or Apple app store.

| Resource | Cost | App or Web resource | Focused information retrieval topics |
|------------------------------------|--------------------|----------------------------|--|
| FirstLine (Spectrum) ⁵⁷ | Free | App/Web | Drug selector for antibiotics |
| Human Dx | Paid ⁵⁸ | App | Diagnostic case studies |
| Geeky Medics | Freemium | App | Procedure support, study aid |
| General Medical Council | Free | Web | Drugs, diagnostic & treatment guidelines, ID management, CME, procedures (British) |
| MDonCall | Paid | App | Point of care guidelines |
| Micro Guide | Free | App | Drugs (Antibiotics) (British) |
| MKSAP | Paid | Web/App | Exam prep for medical students |
| NICE Guidelines | Free | Web | Evidence-based care guidelines (UK only) |
| PocketDr | Freemium | App | Point of care |
| Picmonic | Freemium | App | Medical educational support tool |
| RightBreath | Freemium | App | Pill finder |
| Read by QxMd/Medscape/WebMD | Paid | App | Journal articles/custom feeds |
| StatworkUp DDX Clinical Guide | Paid | App | Drugs, diagnostic & treatment guidelines, mgmt., clinical calculators, CME |
| Touch Surgery (Medtronic) | Freemium | App | Surgical training and use of simulations |
| ToxBase | Free (w/in UK) | App | Toxicity, overdose care management (Scottish) |
| UCSF Hospitalist Handbook | Free | Web/App | Drugs, diagnostic & treatment guidelines mgmt., clinical calculators, CME, procedures |
| UCSF Outpatient Handbook | Free | Web/App | Drugs, diagnostic & treatment guidelines, mgmt., clinical calculators, CME, procedures |

⁵⁷ In partnership with the World Health Organization.

⁵⁸ Must be a medical professional to join the Human Dx community.

C.3 Review of Key APIs

A range of clinical decision support APIs have been developed that provide healthcare professionals with relevant and actionable information at the point of care. These APIs can be seamlessly integrated into health system platforms in a tailored fashion to allow users access to an application program, including those delivering PCOR data. Several APIs were built to accomplish these goals with varying results.

The most well-known of these APIs (described here) market to other businesses, rather than to individual end users.

- **First Data Bank National Drug Data File (FDB NDDF).** This is the premier source of drug interaction data; provides detailed information on drug/drug, drug/disease, drug/allergy, and drug/food interactions. NDDF Also provides detailed information on drug pharmacology, including dosing guidance, adverse event tracking, lab monitoring, etc. It is delivered as a set of data files to be imported into a Relational Database Management System (RDBMS) (e.g., Oracle, MS SQL Server, PostgreSQL) and a 2,000+ page manual. The engineering resources required to implement FDB's NDDF into an EHR are challenging. FDB created an API for their customers to use, but it was not widely adopted until FDB created a progressive web app to their API that showed FDB's customers how lower the cost of implementation of the API.⁵⁹
- **National Library of Medicine MEDLINE API.** First published in the 1970s, the MEDLINE API required specialized training via a series of courses on how to use the API to retrieve clinical citations from MEDLINE's database of more than 20 million journal citations. Medical librarians, as part of the job responsibilities, were required to learn how to use the MEDLINE API. It wasn't until the NLM published its PubMed web page that physicians, residents, and medical students started conducting their own MEDLINE literature searches.
- **National Library of Medicine UMLS API.** The UMLS is the premier source of clinical semantic primitives: language-independent clinical concepts that are mapped to language-specific terms drawn from controlled clinical vocabularies via a "meta-thesaurus," and a clinical semantic network that allows for the identification of clinical terms within the clinical semantic network of a specific clinical term. Like the FDB NDDF, the NLM released UMLS as a set of data files in 1986 for medical informatics research and to support semantic interoperability between EHR/EMR systems. The lack of a value proposition for EMR/EHR vendors meant that no EMR/EHR system widely adopted the UMLS. However, in 2015 GE Healthcare used the UMLS for a purpose-built EMR deployed to the Rio 2016 Olympics that supported the multiple languages of Olympic athletes requiring care from the Portuguese-speaking physicians in the Olympic Village. However, the NLM's API to the UMLS has not found widespread adoption.⁶⁰ The CEDAR RI utilizes UMLS data files to map from search terms and artifact keywords

⁵⁹FDB MedKnowledge (2023). First Databank. Available at: <https://www.fdbhealth.com/solutions/medknowledge-drug-database>.

⁶⁰UMLS API Home. National Library of Medicine. Available at: <https://documentation.uts.nlm.nih.gov/rest/home.html>.

to concepts to provide enhanced search capabilities such as synonym searching and clinical concept code searching.

- **Epic App Orchard/Cerner App Gallery.** EHR vendors Epic and Cerner control a combined 85% of the EHR market.⁶¹ They rely on API technology to permit third-party app developers to easily integrate their apps into the EHR. This enables the app developers an additional way to reach customers and provide complimentary and specialized data directly to the clinician without the need to leave the EHR window.^{62 63}

C.4 Literature Search for Overview of API Adoption

To gather information related to healthcare adoption of APIs, the MITRE CEDAR team identified key themes and questions to structure the review:

1. How do APIs provide opportunity to improve scientific research?
2. Are there significant clinical or medical adoption *challenges* to highlight, when reviewing API adoption in healthcare?
3. Are there significant clinical or medical adoption *opportunities* to highlight, when reviewing API adoption in healthcare?

The CEDAR team conducted a literature search to identify potential case studies and existing articles on API adoption challenges and opportunities. Key word strings searched included:

- “clinical” AND (“API” OR “application programming interface”) AND “adoption”
- “clinical” AND (“API” OR “application programming interface”) AND “adoption challenges”
- “clinical” AND (“API” OR “application programming interface”) AND “adoption opportunities”
- “clinical” AND (“API” OR “application programming interface”) AND “sustainment”
- “medical” AND (“API” OR “application programming interface”) AND “adoption”
- “medical” AND (“API” OR “application programming interface”) AND “adoption challenges”
- “medical” AND (“API” OR “application programming interface”) AND “adoption opportunities”
- “medical” AND (“API” OR “application programming interface”) AND “sustainment”
- “clinical API” AND “adoption”
- “clinical API” AND “case study”

⁶¹ Scarborough, N. (2022) EHRs Ranked by Market Share. Healthgrades. Available at: <https://www.healthgrades.com/pro/chrs-ranked-by-market-share?tpc=pro>.

⁶² Home - Vendor Services (2019). Epic. Available at: <https://vendorservices.epic.com/>.

⁶³ About Us (2023). Oracle. Available at: <https://code.cerner.com/about>.

- “health information” AND “API adoption”
- “health information” AND “API”

Databases explored included: Google Scholar, PubMed, New England Journal of Medicine (NEJM), Learning Health Systems (LHS), HealthIT.gov over a 5-year lookback period between 2019 and 2022. Table 7 summarizes a sample of the search findings.

Table 7: Sample of Search Results for Overview of API Adoption

| Databases Explored | “clinical” AND (“API” OR “application programming interface”) AND “adoption” | “clinical” AND (“API” OR “application programming interface”) AND “sustainment” | “medical” AND (“API” OR “application programming interface”) AND “adoption” | “medical” AND (“API” OR “application programming interface”) AND “sustainment” |
|---------------------------|---|--|--|---|
| Google Scholar | 12,200 articles | 129 articles | 16,700 articles | 248 articles |
| PubMed | 17 | 0 | 15 | 0 |
| NEJM | 5 | 0 | 5 | 0 |
| LHS | 5 | 14 | 669 | 13 |
| HealthIT.gov | 14 | 12 | 13 | 11 |

Appendix D End User Engagement With CEDAR Search Interface

The CEDAR team conducted an informal assessment of the digital health tools used by clinicians, medical students, clinical researchers, grant writers, and patients to identify the information retrieval objectives of these specific categories of users. The CEDAR team also informally queried medical librarians to identify the data resources that they consult when responding to requests from physicians, physicians assistants, clinical researchers, and grant writers.

D.1 Use Cases

The following multiple use cases for CEDAR were identified from the 2022 pilot and from discussions with potential future users of CEDAR:

1. *Evidence-based clinical guidance at the point of care* – These point of care information retrieval tasks were performed by medical students and by resident, teaching, and community physicians.
2. *Research into an area of clinical information* – Evidence-based best practices for the preparation of community grand rounds presentations, specialty society presentations, morbidity and mortality conferences, grant proposals, and research papers. These information retrieval tasks were performed by medical librarians in response to requests from medical students, residents, and teaching and community physicians.
3. *As a training tool and general use information resource* – Evidence-based training of physicians, residents, medical students, nurse practitioners, physician assistants, and other professionals.

D.2 User Groups

Users are grouped into clinical and nonclinical users. Direct patient care users are those individuals who write orders such as prescriptions, lab and diagnostic tests. Nonclinical and indirect patient care users are the recipients of orders or are reviewing data for research purposes.

Direct patient care users include:

1. Physicians, residents, and medical students
2. Nurses and nurse practitioners
3. Physician assistants
4. Pharmacists
5. Emergency medical technicians

Indirect patient care users include:

1. Medical librarians
2. Clinical researchers
3. Grant writers
4. Patients
5. EMR/EHR developers
6. Clinical users engaged in deeper research tasks

The classes of information retrieval tasks (use cases) are provided in the following table. These are paired with the user groups that are likely to be executing these use cases within the CEDAR user interface.

Table 8: Information-Retrieval Tasks by User Category

| Information retrieval objective | Medical librarians | Physicians & medical students | Other clinicians (e.g., NPs, PAs, pharmacists, nurses) | Clinical researchers and grant writers | EMR/EHR developers |
|---|---------------------------|--|---|---|---------------------------|
| Access to clinical case studies for CME and for preparation for examinations. | No | Yes | Yes | No | No |
| Conduct literature search for clinical evidence in support of presentations to community grand rounds, medical society meetings, and morbidity and mortality conferences. | Yes | Yes | Yes | No | No |
| Conduct literature search to develop discussion points for journal clubs. | Yes | No | No | No | No |
| Conduct literature search for clinical evidence in support of research proposals and responses to RFPs. | Yes | No | No | Yes | No |
| Point of care access to evidence-based primary prevention guidelines for disease prevention. | No | Yes | Yes | No | Yes |
| Point of care access to evidence-based secondary prevention guidelines for chronic disease screening. | No | Yes | Yes | No | Yes |
| Point of care access to evidence-based tertiary prevention guidelines for the management of patients with chronic disease and for the management of acute clinical problem. | No | Yes | Yes | No | Yes |
| Point of care access to evidence-based differential diagnosis guidelines for the prioritization of diagnostic plans. | No | Yes | No | No | Yes |

Appendix E IT Standards

This environmental scan included a reassessment of the existing and emerging health IT standards that were considered as a part of ES20's assessment of relevant information that may play a role for the CEDAR references implementation. Based on the information that has already been included as a part of the current reference implementation, additional detail about aspects of the FHIR standard (see Section E.1) has been included based on the pivotal role that the standard plays within the CEDAR API. The CEDAR API also uses standardized vocabulary sets (see Section E.2) for object classification, within the searches and identification of related elements for a search.

E.1 FHIR Citation Resource

CEDAR uses the FHIR Citation⁶⁴ resource as the main artifact in the CEDAR API. The Citation resource represents a reference to any knowledge artifact for purposes of identification and attribution. The Citation resource focuses on describing any aspect of identification, location, authorship, and contributorship (artifact metadata) of a journal article, report, document, resource, or other knowledge artifact. The Citation resource also provides search capability for reports of research or scholarly publications using the metadata contained in such resources.

The Citation resource has multiple elements containing metadata that describe the Citation resource itself, such as the timestamp the Citation resource is created by CEDAR. The Citation resource uses the cited Artifact element for metadata that describe the article or artifact being cited, such as the status of a cited article on the USPSTF repository.

To adapt the Citation resource for CEDAR's usage, CEDAR created several extensions and search parameters for the FHIR base Citation resource. The extensions provide additional metadata, such as strength of recommendation and quality of evidence that is not directly represented in the base Citation resource. The additional Citation search parameters allow clients to search for artifacts more accurately.

Section 4.1.1 describes technical challenges to use of the Citation resource.

E.2 Standard Vocabularies

CEDAR classifies artifacts using concepts from the following standard vocabularies:

- Medical Subject Headings (MeSH)⁶⁵
- MedlinePlus Health Topics⁶⁶
- Systematized Nomenclature of Medicine Clinical Terms Clinical Terms (SNOMED-CT)⁶⁷

⁶⁴Citation Resource – Content (2023). HL7.org. Available at: <https://build.fhir.org/citation.html>.

⁶⁵Medical Subject Headings (2023). National Library of Medicine. Available at: <https://meshb.nlm.nih.gov>.

⁶⁶Health Topics. MedlinePlus. Available at: <https://medlineplus.gov/healthtopics.html>.

⁶⁷SNOMED CT (2019). National Library of Medicine. Available at: <https://www.nlm.nih.gov/healthit/snomedct/index.html>.

- International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM)⁶⁸
- RxNorm⁶⁹

Artifacts are classified by matching their keyword metadata to concept synonyms extracted from the Unified Medical Language System (UMLS) Metathesaurus.⁷⁰ Each concept is then mapped to one or more of the standard vocabularies.

The assigned concepts are used by the CEDAR API, both to support search by synonym and concept, and to populate the cited artifact classifiers section in the FHIR Citation resource.

⁶⁸International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM). National Center for Health Statistics. Available at: <https://www.cdc.gov/nchs/icd/icd-10-cm.htm>.

⁶⁹RxNorm (2022). National Library of Medicine. Available at: <https://www.nlm.nih.gov/research/umls/rxnorm/index.html>.

⁷⁰Metathesaurus (2016). National Library of Medicine. Available at: https://www.nlm.nih.gov/research/umls/knowledge_sources/metathesaurus/index.html.

Appendix F Repository Metadata Dependencies

Section 3.1.1 of this document summarizes the techniques used to extract artifact lists and metadata from each repository. This appendix provides additional details about the source of each metadata element for each repository.

F.1 HTML and PDF Metadata

As shown in section 3.1.1, the USPSTF and EPC CEDAR indexers extract artifact metadata from HTML and PDF documents.

The following PDF metadata attributes are supported by CEDAR: Subject, Keywords, ModDate and CreationDate.

HTML documents embed metadata in their header using meta tags. The following example illustrates use of this element

```
<meta name="DCTERMS.description" content="A sample description">
```

The meta tag has a name attribute that identifies the type of metadata and a content attribute that supplies the value for that metadata. CEDAR supports HTML meta tags with the following name values:

- description and DCTERMS.description
- keywords, citation_keywords and Keywords with content as a list of keywords or phrases separated by “,” or “;”
- citation_doi
- DCTERMS.issued, DCTERMS.created, DC.Date, DC.date, citation_publication_date, citation_date, datereviewed and datecreated
- warning with content that includes “historical reference only” will result in a CEDAR status of “archived”

In addition to the meta elements, CEDAR will also look for publication date in div elements with an id attribute of “page-created” and span elements with an id attribute of “lblTitleDate” or “lblTitleId”.

F.2 CDS Connect

The list of artifacts to index is obtained by parsing a CDS Connect-supplied JSON document. The following skeleton example omits unused properties.

```
[  
  {  
    "nid": "27816",  
    ...  
  },  
  ...  
]
```


CEDAR extracts the values of the `nid` properties (e.g., “27816” in the example) from this document and relies on:

1. The URL for the JSON document remaining stable
2. The top level of the document being an array
3. Each member of the array being an object with a `nid` property

The extracted `nid` values are used to construct a URL, e.g., https://cds.ahrq.gov/cds_api/27816, where 27816 is the `nid` value to retrieve the metadata for each artifact as a JSON document. The following a skeleton example omits unused properties.

```
{
  "title": "...",
  "description": "...",
  "status": "active",
  "artifact_type": "Data Summary",
  "creation_and_usage": {
    "keywords": [
      "Chronic Pain",
      ...
    ]
  },
  "organization": {
    "mesh_topics": [
      "Analgesics, Opioid",
      ...
    ]
  },
  "supporting_evidence": {
    "recommendation_statement": [
      {
        "strength_of_recommendation": "strength",
        "quality_of_evidence": "quality",
        ...
      }
    ]
  },
  "repository_information": {
    "publication_date": "2020-11-30",
    ...
  },
  ...
}
```

CEDAR relies on the:

1. Structure of the URL for each artifact remaining stable
2. Top level of the document being an object
3. Presence of a `title` property with a string value

4. Presence of a description property with a string value
5. Presence of an artifact_type property with a string value
6. Presence of a status property with one of the following string values: draft, active, retired, unknown, or retracted
7. Presence of creation_and_usage.keywords and organization.mesh_topics properties, each of which is an array of string values that correspond to artifact keywords
8. Presence of a supporting_evidence.recommendation_statement property whose value is an array of objects, each having strength_of_recommendation and quality_of_evidence properties with string values
9. Presence of a repository_information.publication_date property with a string value formatted as 'YYYY-MM-DD' to represent the publication date

F.3 USPSTF

A list of USPSTF artifacts and associated metadata is extracted from a USPSTF-supplied JSON document <https://data.uspreventiveservicestaskforce.org/api/json>. CEDAR relies on:

1. The URL for the JSON document remaining stable
2. The top level of the document being an object
3. The presence of the following properties (whose expected values are described in this section): generalRecommendations, specificRecommendations, tools, grades and categories

F.3.1 General Recommendations

CEDAR extracts metadata about general recommendations from the generalRecommendations property of the USPSTF JSON document. CEDAR relies on the value of the generalRecommendations property being an object with one sub property for each general recommendation, as illustrated in the following example.

```
{
  "generalRecommendations": {
    "recommendation_id": {...},
    ...
  },
  ...
}
```

CEDAR uses the sub property names (recommendation_id in the example) for cross-referencing from specific recommendations. The value of each object ({...} in the example) is expected to follow the structure illustrated here (unused properties omitted for brevity).

```
{
  "topicType": "Screening",
  "uspstfAlias": "...",
  "title": "...",
  "clinical": "...",
```

```

"keywords": "Autism|Developmental Delay|Spectrum",
"pubDate": "2016-02-16",
"categories": [
  "1",
  ...
],
...
}

```

CEDAR relies on the presence of a:

1. `topicType` property with a string value
2. `uspstfAlias` property whose value is a string that is the same as the final part of the URL for the general recommendation. E.g., if the `uspstfAlias` has a value of `autism-screening`, CEDAR assumes the recommendation web page will be found at <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/autism-screening>
3. `title` property with a string value
4. `clinical` property with a string value that may include HTML markup
5. `keywords` property with a string value that contains a | separated list of keywords or phrases
6. `pubDate` property with a string value formatted as ‘YYYY-MM-DD’ to represent the publication date
7. `categories` property whose value is an array of strings, each of which identifies a category further described in the top-level `categories` property of the document

F.3.2 Specific Recommendations

CEDAR extracts metadata about specific recommendations from the `specificRecommendations` property of the USPSTF JSON document. CEDAR relies on the value of the `specificRecommendations` property being an array of objects, each of which describes one specific recommendation, as illustrated here.

```

{
  "specificRecommendations": [
    {...},
    ...
  ],
  ...
}

```

The value of each object (`{...}` in the example) is expected to follow the structure illustrated here (unused properties omitted for brevity).

```

{
  "id": 426,
  "title": "...",
  "grade": "A",
  "text": "...",

```

```

"general": "389",
"tool": [
  "196",
  "197"
]
}

```

CEDAR relies on the presence of a:

1. `id` property with a string value
2. `title` property with a string value
3. `grade` property whose string value identifies a grade further described in the top-level `grades` property of the document
4. `text` property with a string value that may include HTML markup
5. `general` property whose string value corresponds to a general recommendation sub-property of the top-level `generalRecommendations` property of the document
6. `tool` property whose value is an array of strings, each of which identifies a tool further described in the top-level `tools` property of the document

F.3.3 Tools

CEDAR extracts metadata about tools from the `tools` property of the USPSTF JSON document. CEDAR relies on the value of the `tools` property being an object with one sub property for each general recommendation as illustrated here.

```

{
  "tools": {
    "tool_id": {...},
    ...
  },
  ...
}

```

CEDAR uses the sub property names (`tool_id` in the example) for cross-referencing from specific recommendations. The value of each object (`{...}` in the example) is expected to follow the structure illustrated here (unused properties omitted for brevity).

```

{
  "url": "...",
  "title": "...",
  "keywords": "Breast|Cancer"
}

```

CEDAR relies on the presence of a:

1. `url` property with a string value that is an absolute URL to the tool web page
2. `title` property with a string value
3. `keywords` property with a string value that contains a `|` separated list of keywords or phrases

CEDAR will supplement the metadata with metadata extracted from the artifact at the url value - see the “HTML and PDF Metadata” section.

F.3.4 Categories

CEDAR extracts artifact category definitions from the categories property of the USPSTF JSON document. CEDAR relies on the value of the categories property being an object with one sub property for each category as illustrated here.

```
{
  "categories": {
    "3": {
      "name": "Cancer"
    },
    ...
  },
  ...
}
```

CEDAR uses the sub property names (3 in the example) for cross-referencing from general recommendations. The sub-property values are expected to be an object that follows the illustrated structure with a single name property of type string (value of Cancer in the example).

F.3.5 Grades

CEDAR extracts artifact grade definitions from the grades property of the USPSTF JSON document. CEDAR relies on the value of the grades property being an object with one sub property for each grade as illustrated here.

```
{
  "grades": {
    "A": [
      "The USPSTF recommends the service. There is high certainty that the net benefit is substantial.",
      ...
    ],
    ...
  },
  ...
}
```

CEDAR uses the sub property names (A in the example) for cross-referencing from specific recommendations. The sub-property values are expected to be an array that follows the structure illustrated with one or more string values, only the first of which is used.

F.4 EHC

The list of artifacts and their metadata is obtained by parsing an EHC-supplied XML document. A skeleton example that omits unused elements and attributes is shown here:

```

<response>
  <item>
    <Title>...</Title>
    <Link>...</Link>
    <Description>...</Description>
    <Health-Topics>Chronic Pain, Mycetozoa</Health-Topics>
    <Product-Type>...</Product-Type>
    <Publish-Date>March 24, 2021</Publish-Date>
    <Status>...</Status>
    <Keywords>Chronic Pain, Mycetozoa</Keywords>
    <Citation>... 10.23970/AHRQEPCCER190 ...</Citation>
  </item>
  ...
</response>

```

CEDAR iterates over each `item` child element of the root response element and then uses relative XPath expressions to extract the string values of each child element of each `item`. This approach relies on element names remaining consistent. CEDAR also makes the following additional assumptions:

1. The values of the `Health-Topics` and `Keywords` elements are comma separated lists of keywords or phrases
2. The value of the `Publish-Date` element is formatted as illustrated (Month Day, Year)
3. DOIs embedded with the `Citation` element will begin with “10.” followed by 4 – 9 digits, a “/” and then the remainder of the DOI. Preceding or following text is supported provided at least one whitespace character follows the DOI. An example is shown above.

F.5 EPC

The list of artifacts is obtained by parsing the HTML of the EPC web site. CEDAR starts at the EPC search page (https://www.ahrq.gov/research/findings/evidence-based-reports/search.html?search_api_fulltext=&page=0) and follows the links to each page in the list of results.

Links to following pages are identified by looking for an HTML `li` element with a class of `pager__item--next` that has a child `a` element, e.g.:

```

<li class="pager__item--next">
  <a href="?search_api_fulltext=&page=1" ...>
    ...
  </a>
</li>

```

On each page of the list, artifacts are identified by looking for `div` elements with a class of `views-row` that are descendants of a `div` element with a class of `view-content`. An example of the HTML structure that CEDAR expects is shown here:

```

<div class="view-content">
  <div class="views-row">
    <div class="views-field views-field-title">
      <span class="field-content">

```

```

    <a href="...">
      ...
    </a>
  </span>
</div>
<div class="views-field views-field-field-timestamp">
  <span class="field-content">Date: October 2020</span>
</div>
<div class="views-field views-field-field-epc-type">
  ... <span class="field-content">In Progress</span>
</div>
...
</div>
...
</div>

```

The following types of changes would impact the CEDAR indexer:

1. Changes to element types, e.g., using a p element instead of a div
2. Changes to element nesting, e.g., moving a span out of the current parent div
3. Changes to class names, e.g., renaming views-field-field-timestamp to views-field-timestamp

CEDAR supplements the metadata extracted from the artifact list with metadata extracted from the artifact web page (the URL in the href attribute of the a element in the example) - see the “HTML and PDF Metadata” section for additional details.

F.6 SRDR+

The list of artifacts and their metadata is obtained by parsing an SRDR-supplied JSON document. A skeleton example that omits unused elements and attributes is shown here:

```

{
  "projects": [
    {
      "id": 1343,
      "name": "...",
      "description": "...",
      "doi": "10.7301/Z08G8HMP",
      "mesh_descriptors": [
        {
          "name": "Colorectal Neoplasms",
          ...
        }
      ],
      "published_at": "2015-07-23T21:39:39.000Z",
      "deleted_at": "...",
      ...
    },
    ...
  ],
  ...
}

```

```
]
}
```

CEDAR iterates over each child of the `projects` property (expected to be an Array) and relies on each child being an object with:

1. An `id` property of type string whose value is used to construct a URL for the public facing artifact web page as follows:
`https://srdplus.ahrq.gov/public_data?id=id&type=project` where *id* is the value of the `id` property
2. A `name` property of type string
3. A `description` property of type string
4. A `doi` property of type string whose value is just the DOI (i.e. does not include any other text)
5. A `mesh_descriptors` property of type array whose child elements are of type object, each with a `name` child property of type string that contain the name of a MeSH node
6. A `published_at` property of type string formatted as shown if the artifact has been published
7. A `deleted_at` property of type string with the same format as `published_at` if the artifact has been deleted

Appendix G Abbreviations and Acronyms

| Term | Definition |
|---------------|--|
| AAFP | American Academy of Family Physicians |
| AHRQ | Agency for Healthcare Research and Quality |
| AMIA | American 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 |
| C-FAIR | CEDAR FAIR Assessment Tool |
| CMS | Centers for Medicare & Medicaid Services |
| COKA | COVID-19 Knowledge Accelerator |
| CONOPS | Concept of Operations |
| CTDRR | CoreTrustSeal Trustworthy Data Repositories Requirements |
| DOI | Digital Object Identifier |
| EHC | Effective Health Care |
| EHR | Electronic Health Record |
| EPC | Evidence-based Practice Center |
| ES20 | CEDAR Environmental Scan 2020 |
| ES23 | CEDAR Environmental Scan 2023 |
| FAIR | Findable, Accessible, Interoperable, and Reusable |
| FDB | First Data Bank |
| FFRDC | Federally Funded Research and Development Center |
| FHIR® | Fast Healthcare Interoperability Resource |
| FMG | FHIR Management Group |
| GRADE | Grading of Recommendations Assessment, Development, and Evaluation |
| HHS | Department of Health and Human Services |
| HL7® | Health Level 7® |
| HTML | Hypertext Markup Language |

| Term | Definition |
|------------------|---|
| HTTPS | Hypertext Transfer Protocol |
| IT | Information Technology |
| JSON | JavaScript Object Notation |
| MeSH® | Medical Subject Headings |
| NDDF | National Drug Data File |
| NGC | National Guideline Clearinghouse™ |
| NIAID | NIH National Institute of Allergy and Infectious Disease |
| NIH | National Institutes of Health |
| NLM | National Library of Medicine |
| NOAA | National Oceanic and Atmospheric Administration |
| NSF | National Science Foundation |
| PCOR | Patient-Centered Outcomes Research |
| PDF | Portable Document Format |
| RDA | Research Data Alliance |
| RDBMS | Relational Database Management System |
| RI | Reference Implementation |
| RxNORM | Standardized nomenclature for clinical drugs (by National Library of Medicine) |
| SME | Subject-matter expert |
| SNOMED-CT | Systematized Nomenclature of Medicine-Clinical Terms |
| SRDR | Systematic Review Data Repository™ |
| SRDR+ | Systematic Review Data Repository Plus |
| TDR | Trustworthy Digital Repositories |
| TRUST | Transparency, Responsibility, User Focus, Sustainability, Technology |
| UI | User interface |
| UMLS® | Unified Medical Language System® |
| URL | Uniform Resource Locator |
| USPSTF | United States Preventive Service Task Force |
| VA | Department of Veterans Affairs |

| Term | Definition |
|-------------|----------------------------|
| XML | Extensible Markup Language |