

AHRQ CEDAR

Final Project Report

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CMS Alliance to Modernize Healthcare (The Health FFRDC)

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Executive Summary

Considerable delay exists between the production of research evidence and its adoption for use in clinical settings. The Agency for Healthcare Research and Quality (AHRQ) maintains repositories of patient-centered outcomes research findings and other research evidence developed through different programs. The research evidence ranges from systematic reviews and clinical practice recommendations to clinical decision support tools, and each program developed different platforms for dissemination. Discovery and retrieval of content remains manual and requires users to search each repository independently.

AHRQ aims to improve the efficiency of discovering and disseminating evidence-based resources into practice through the CEDAR project. CEDAR stands for the AHRQ Center for Evidence and Practice Improvement (CEPI) Evidence Discovery And Retrieval. CEDAR is intended to make the research evidence and findings in AHRQ resources more FAIR (Findable, Accessible, Interoperable, and Reusable) through the development of a standards-based application programming interface (API) that supports the search, access, and use of research evidence in certain AHRQ repositories and programs. Released as an open source project, CEDAR will give developers the ability to integrate AHRQ evidence directly into their existing systems. Researchers, clinicians, policymakers, patients, and others who rely on AHRQ's evidence can then access the information through the third-party applications.

The CEDAR Project Report describes the first two years of the CEDAR project and its initial build. The report reviews accomplishments related to an initial environmental scan, stakeholder outreach, technical development, pilot testing, and project management and identifies recommendations for future CEDAR development.

Between September 2020 and September 2022, AHRQ, with support from The MITRE Corporation, accomplished significant progress on CEDAR.

- The team developed and launched CEDAR, a comprehensive reference implementation that includes the FHIR-based CEDAR API. Users can experience how CEDAR works by searching for resources through a demonstration of two user interfaces on the AHRQ website. CEDAR is open source and freely available for use.
- The team built a tool named C-FAIR to quantify FAIR access to CEPI information. MITRE demonstrated that the CEDAR API increased FAIRness across each of the CEPI repositories by the end of the project.
- Regular, frequent stakeholder input allowed the team to understand different perceptions, needs, and uses of CEPI evidence and to incorporate feedback into CEDAR's iterative development.

- A pilot with the American Academy of Family Physicians informed CEDAR's development and initial release. The pilot confirmed that it is feasible and requires a relatively low amount of effort to incorporate CEDAR into an organization's system. Nine researchers and nine clinicians participated in the pilot activities. Early qualitative findings show general positive receptivity to the CEDAR API, including:
 - Seven clinicians reported an increase of the quantity and six clinicians reported improved quality of the information they were able to locate when using the CEDAR application.
 - All researchers reported confidence in the search results, noting that the results came from trustworthy sources, and all but one researcher was receptive to using CEDAR in future work.
 - All clinicians stated that they had gained knowledge about at least one CEPI resource as a direct result of participating in the pilot.
 - The pilot overall demonstrated that end users could be receptive to using future publicly available applications of CEDAR, with participants observing that CEDAR has the potential to save time.

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Introduction

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

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

Objectives and Outcomes

The purpose of the CEDAR project was to provide timely and efficient access to research evidence that CEPI maintains in several of its evidence repositories, resources, and programs. In this way, end users of this information can make healthcare decisions that are more informed by the available evidence, and they will also be able to find the evidence more quickly and easily from a single point of access that supports computer-to-computer interaction. The focus on computer-enabled access through a standards-based API allows CEDAR to be integrated into a variety of systems, which in turn allow for user interfaces that meet the needs of a variety of users such as clinicians, researchers, implementers, patients, and others. The experience of each user will be tailored by developers integrating CEDAR into systems and would reflect the functionality that their particular end users would find most useful.

CEDAR was intended to index evidence from CDS Connect, the Effective Health Care Program, Evidence-based Practice Centers, the Systematic Review Data Repository (which later evolved to the Systematic Review Data Repository Plus), and the U.S. Preventive Services Task Force.

To foster timely and efficient access, the project incorporated and applied the FAIR Guiding Principles to the evidence and the repositories themselves. To make this evidence more FAIR,

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

MITRE developed a prototype infrastructure demonstrating standards-based, API-enabled discovery and retrieval of the evidence in CEPI repositories.

Project Tasks

The CEDAR project consisted of five primary tasks:

- Performance of an environmental scan
- Development of a reference implementation
- Pilot testing
- Outreach and engagement
- Project management

MITRE assigned a distinct project team to each task, which operated pursuant to discrete schedules with distinct products. Task teams engaged in continuous cross-pollination and collaboration across the project. In this way, all teams and tasks shared and leveraged the information and knowledge gleaned in each task area. For example, the stakeholder outreach task team shared their findings and information with the development and pilot task teams alike for iteration of the API and pilot client application.

Milestones and Accomplishments

Throughout the CEDAR project's 2-year period of performance, the project team met key milestones and accomplishments.

- **Environmental Scan:** AHRQ publicly released the final iteration of the Environmental Scan² on the CEDAR project page of the AHRQ website in April 2021.
- **Reference Implementation:** MITRE developed and iterated on a comprehensive CEDAR reference implementation; developed a client user interface to demonstrate the API; created an evaluation tool to assess changes in adherence to FAIR Guiding Principles; and engaged in multiple Health Level Seven (HL7) initiatives, both as a tester and as a real-world use case.
- **Pilot:** MITRE partnered with the American Academy of Family Physicians (AAFP) to demonstrate the ability of a third-party organization to integrate CEDAR API into an application external to the AHRQ infrastructure. AAFP was also able to offer a wide variety of end users with whom to test the utility and functionality of the CEDAR API through "CEDAR Search," an AAFP client application.

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

- **Outreach:** MITRE conducted a variety of stakeholder engagement and outreach activities over the course of the 2-year project period to raise awareness of CEDAR and inform CEDAR development with information and opinions gathered from stakeholders. MITRE subsequently provided a recommended set of communications channels and messaging for AHRQ and its Office of Communications to use in future efforts to raise awareness of the CEDAR project. In addition, MITRE presented at a variety of conferences or smaller meetings to further share information about the project during 2021 and 2022.
- **Project Management:** MITRE’s project and program leadership ensured effective project operations, including staffing, budgeting, invoicing, delivery, quality assurance, and related activities, throughout the 2 years of the project.

Environmental Scan

During the first 6 months of the project, MITRE conducted an environmental scan to inform the development of CEDAR. The scan increased the team’s knowledge and understanding of the CEPI repositories, including their technical specifications and their communities of end users. The scan also summarized the relevant FAIR Guiding Principles and existing tools that measure FAIRness, relevant health information technology standards for potential use, and other tools and resources that contain or share PCOR and other research evidence and findings.

The scan identified technical and nontechnical risks to the successful development of CEDAR; in consideration of these, MITRE made multiple recommendations for both short-term and long-term consideration. Appendix A tracks these recommendations, with a retrospective review of whether or not they were incorporated into the project (or, if long-term, should still be considered).

Reference Implementation

The core of the CEDAR project is the Reference Implementation (RI), a web-based service that imports and indexes PCOR and other research evidence from several CEPI repositories, making this content searchable and available via an open-source, standards-based API. Its overarching goal is to make it easy for end users to find and access the information that meets their needs in the most efficient way possible.

Two design decisions are central to this overarching goal.

- Developing the RI as an API (rather than a website) means that CEDAR can support a wider variety of use cases. Research evidence is valuable to a variety of end users; an API allows the development of different client applications with potentially different user interfaces and approaches to finding information. End users can also integrate CEDAR directly with a diversity of existing applications, ranging from electronic health record systems and patient portals to mobile applications for clinical research.
- Using HL7’s Fast Healthcare Interoperability Resources® (FHIR®) in the API enables client application developers to integrate CEPI research findings into their existing systems via CEDAR without the burden of significant customization. FHIR is built upon modern Internet standards such as REpresentational State Transfer (REST) and JavaScript Object Notation (JSON), lowering the “learning curve” for software developers who are new to FHIR.

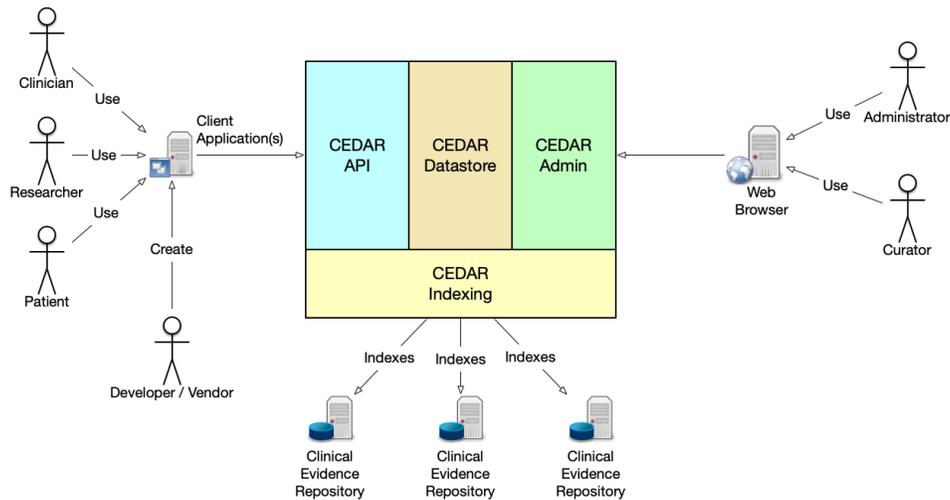
Development Process

The CEDAR RI followed an Agile process characterized by regular feedback from and partnership with the AHRQ project team. Because RI development prioritized use cases needed to achieve AHRQ’s goals, the result serves a wide range of end users, including system and application developers, patients, clinicians, researchers, and librarians. MITRE developed high-level and detailed user stories based on these end users and their respective objectives. Findings from an environmental scan, stakeholder discussions, outreach interviews, assessment against FAIR criteria, and collaboration with the FHIR community informed the evolution of these user stories. Through its Agile process, MITRE iteratively refined the features and functions available in the RI at <https://cds.ahrq.gov/cedar/>.

CEDAR RI Concept of Operations

The CEDAR RI consists of four components working in concert: (1) CEDAR Indexing, (2) CEDAR Datastore, (3) CEDAR Admin, and (4) CEDAR API. **Figure 1** shows the main functions of the CEDAR Concept of Operations and its associated stakeholders. Arrows indicate interactions from the initiator to the target.

Figure 1. CEDAR Concept of Operations



CEDAR Indexing and Datastore

CEDAR imports and indexes artifacts from each of the CEPI source repositories and makes these artifacts searchable within the CEDAR RI. AHRQ created the individual CEPI repositories over time with varied architectures and interfaces, making the efficient discovery and retrieval of evidence from multiple CEPI resources challenging. One of the main benefits of the CEDAR RI is that it makes CEPI evidence available through a single interface in a standard format, enabling adherence to the FAIR Guiding Principles. CEDAR accomplishes this goal by:

- Importing CEPI artifact data and metadata (i.e., extracting the data and metadata and mapping it to the CEDAR data model).
- Saving it to the CEDAR Datastore.
- Periodically reindexing and tracking all artifact changes between import runs.

CEDAR's approach to importing reflects the diversity of underlying architectures, data models and schemas, and APIs across the CEPI repositories. The import process consists of two steps: (1) extracting data and metadata from each repository and (2) mapping it to a standard data model.

Each importer's extraction approach is tailored to how the specific repository exposes its data. CEDAR's importers range from accessing RESTful APIs, to parsing large Extensible Markup Language (XML) files, or to extracting information from web pages and Portable Document Format (PDF) files using bespoke web crawlers. Some importers employ multiple extraction techniques, such as retrieving data from both PDFs and JSON APIs. CEDAR favors using well-defined APIs for data import over webpage or document scraping where possible.

After extraction, CEDAR maps the data and metadata extracted from each CEPI repository to a standard representation: the CEDAR RI Artifact model. In the context of CEPI evidence, data are

the descriptive content of an Artifact, such as the full text of a systematic review or tool, while metadata is information about the data that explains its context and makes it easier to discover, use, and manage. Title, status, publication date, and richer characteristics like keywords are all metadata elements. Robust metadata is important because it improves the findability and interoperability of digital assets by enabling end users to search by specific fields, such as publication date or keywords, using a common vocabulary.

The CEPI repositories do not, however, share a common metadata model, so the same metadata elements may have different names or use different vocabularies for their values. Like extraction, the mapping process is customized to how each repository represents its evidence. For some metadata elements, mapping involves straightforward standardization, such as lowercasing text or transforming dates into a single format. In other cases, mapping requires imputing the value for a missing metadata element by leveraging other metadata. For metadata like keywords, CEDAR links repository-defined keywords with clinical concepts in controlled vocabularies and terminologies like Systematized Nomenclature of Medicine (SNOMED) Clinical Terms (SNOMED CT)³ and Medical Subject Headings (MeSH).⁴

The CEDAR Concepts model provides a mapping between the repository-assigned keywords and a set of clinical vocabularies and classification systems. CEDAR Concepts are sourced from the National Library of Medicine’s Unified Medical Language System (UMLS) Metathesaurus, a biomedical thesaurus that identifies synonyms from almost 200 vocabularies.⁵ CEDAR associates an Artifact with zero or more clinical Concepts based on the Artifact’s keywords during metadata mapping to address the common vocabulary requirement. CEDAR uses Concepts in the RI for query expansion, whereby words or phrases are added to a search query to match a larger set of results. For example, by associating Artifacts with Concepts, user searches for “cancer” will also return CEDAR Artifacts related to “malignant neoplasm,” since that is a UMLS synonym of cancer. Linking Artifacts to Concepts improves findability and ensures that CEDAR search results match users’ expectations. Users of systems built with the CEDAR API will expect results to include all related artifacts, regardless of the specific terminology used to describe them. Concepts have the added benefit of associating keywords with controlled vocabularies, such as RxNorm,⁶ SNOMED CT, MeSH, and others. These controlled vocabularies are often used in clinical systems like electronic health records, making it possible to associate CEDAR Artifacts with a patient problem list, for example.

3 SNOMED International, Use SNOMED CT, <https://www.snomed.org/snomed-ct/Use-SNOMED-CT>.

4 National Library of Medicine, Medical Subject Headings, <https://www.nlm.nih.gov/mesh/meshhome.html>.

5 National Library of Medicine, UMLS Metathesaurus, https://www.nlm.nih.gov/research/umls/knowledge_sources/metathesaurus/index.html.

6 National Library of Medicine, RxNorm, <https://www.nlm.nih.gov/research/umls/rxnorm/index.html>.

After extraction and metadata mapping, CEDAR Artifacts persist (i.e., are saved) to a relational database: the CEDAR Datastore. CEDAR periodically reindexes each CEPI repository to fetch new evidence and update existing Artifacts. During reindexing, all changes to saved Artifacts are tracked in the Datastore's Versions model. A CEDAR Artifact may have many Versions, where each Version is a snapshot of the Artifact at a point in time. Developers of systems built with the CEDAR API can offer features that leverage the stored Versions of an Artifact to allow users to understand how the Artifact has evolved over time. Each Version is timestamped, providing information on when a specific Artifact was last updated. In conjunction with the publication date, the last updated date gives insight into the recency of specific evidence. When clinical evidence becomes outdated, CEPI stewards may remove related publications from their repositories. According to the FAIR Guiding Principles, when an Artifact is deleted, the metadata should remain to indicate to a searcher that the Artifact was removed. When CEDAR detects that an Artifact was deleted during reindexing, the system changes its status to "retracted" and keeps the Artifact's metadata to address this aspect of FAIR.

By translating CEPI resources into a uniform data structure described by a consistent vocabulary, CEDAR can aggregate the CEPI resources into one Datastore and expose them via a single interface. CEDAR's modular approach will enable CEDAR to expand and evolve as necessary.

CEDAR API

Client applications can use the CEDAR API to find and retrieve information about the evidence that CEDAR indexes. An API is a set of rules that describes how two systems communicate with each other. The CEDAR API uses a RESTful approach—an architectural style that imposes constraints on how an API functions. REST is typically implemented using Internet technologies like the Hypertext Transfer Protocol (HTTP) and JSON, offering a stateless request/response pattern. Statelessness helps achieve scalability and reduces API complexity.

The CEDAR API uses the FHIR standard. The fundamental building block for organizing data in FHIR is the Resource. A FHIR Resource is a well-specified way to represent a single concept, like a Patient or a Condition. The CEDAR API uses the Citation Resource⁷ to represent and share information about indexed artifacts. The CEDAR API works by accepting requests that specify the artifacts of interest and responding with all matching artifacts as JSON FHIR Citations. The API supports several types of interaction:

- Searching by Artifact text in the title or body of the artifact; CEDAR automatically includes synonyms when conducting searches by text.
- Searching by Artifact keyword as specified by the source repository.
- Searching by Concept; CEDAR maps Artifact keywords to health Concepts in vocabularies like SNOMED-CT or MeSH using the UMLS Metathesaurus.

⁷ Resource Citation – Content. <http://hl7.org/fhir/citation.html>.

- Searching by last updated or publication date; CEDAR allows Artifacts to be filtered by the date that CEDAR detects they have been modified or publication date.
- Searching by Artifact status; each Artifact in CEDAR can have a status of draft, active, unknown, archived, or retracted.
- Searching by Artifact publisher; searches can be scoped by the Artifact source repository.
- Retrieving the full list of repositories indexed by CEDAR.
- Navigating through the MeSH Concept hierarchy tree to find relevant Concepts for searching.

A complete guide to using the CEDAR API can be found in the CEDAR API Getting Started Guide.⁸ Developers who want to experiment with the CEDAR API can leverage the CEDAR API Specification page. The CEDAR API Specification uses Swagger UI, an open-source tool that allows users to visualize and interact with an API without building a client application. CEDAR can take advantage of the Swagger UI because the CEDAR API is documented using the OpenAPI specification. Up-to-date, comprehensive documentation is critical to API ease of use and adoption. The MITRE team has prioritized robust documentation of the CEDAR API to improve the experience of client application developers using the API.

CEDAR Admin

CEDAR Admin is a web-based system dashboard that exposes key information from the other three CEDAR RI components (i.e., Indexing, Datastore, and API) through a user interface. The application uses a combination of charts, tabular data, and graphics to support the analysis of underlying repository data quality and CEDAR system usage. Unlike a static report, CEDAR Admin displays live, dynamically updated data that provide insight about known areas of interest. Due to the potential sensitivity of some administrative information (e.g., search logs and search client Internet Protocol [IP] addresses), access to CEDAR Admin requires authentication and authorization. The system is intended to be used by CEPI repository stewards and the governor of CEDAR.

For CEDAR Indexing, CEDAR Admin shows the status of each importer, including timestamped data on individual runs. The Admin dashboard displays import run data in a tabular format and includes top-level information on time to completion, the artifact count (new, updated, deleted, total), and any errors or warnings. Users can drill down into individual imports and view specific artifacts added or changed during import, including their version history and metadata.

Collectively, these views allow system administrators to gain insight into the status of each CEPI repository importer and triage any issues that may arise.

For the CEDAR API, CEDAR Admin displays information on executed queries. Aggregated search data are shown for the last 10 days and include metrics on the count of all searches,

⁸ See, e.g., https://cds.ahrq.gov/cedar/getting_started.html.

searches by API parameter, and the top 20 search terms. Individual searches can also be viewed within the Search Logs; an individual log shows the key value-pairs for the CEDAR API query, the count of results returned, the total results, the client's IP address, and the time required to execute the search.

For the CEDAR Datastore, CEDAR Admin provides aggregated statistics on the total number of artifacts, artifact count by repository, artifact count by specific dimension (e.g., status, artifact type, keyword), and artifact count by missing attribute (where missing attributes include title, description, keyword, concept, keyword with concept). CEDAR Admin also shows this same information by individual CEPI repository.

Beyond statistics for each repository, CEDAR Admin can also drive improvements to FAIRness by providing transparency into any missing metadata within the control of the repository. For example, repository stewards can see what metadata are missing and add that information, thus allowing stewards to make artifacts more "findable" and increasing adherence to one of the FAIR principles.

The team explored this idea in a curation trial with two repositories (USPSTF and SRDR) in which the CEDAR team explored the feasibility of providing repository stewards with a list of artifacts that were missing metadata (specifically, keywords) and proposed content using MeSH on Demand for the missing metadata. The project team found that the keywords proposed by MeSH on Demand were both broadly correct and complete, review of the proposed keywords for correctness was relatively rapid, and that both the review of proposed keywords for completeness and adding keywords to an artifact required a moderate amount of time (15-30 minutes per artifact) and effort to accomplish. An additional outcome of USPSTF's participation in the curation trial was a recognition that the lack of keywords for some artifacts could be addressed within USPSTF without requiring editing of each artifact. Future work could explore how much the lack of keywords impacts adherence to FAIR principles and whether there is value in repository stewards regularly reviewing the metadata reports produced by CEDAR Admin.

Standards Employed

CEDAR uses several industry standards in its RI. Using standards is critical to achieving interoperability, one of the four FAIR Guiding Principles. Interoperability requires the design, acceptance, and adoption of data standards so that information across settings can be both exchanged and understood. Interoperability hinges on two essential concepts: syntax (also known as structure) and semantics. Syntactic (or structural) interoperability means that data can be exchanged between systems because the systems have agreed on the format for sending and receiving information. With semantic interoperability, the meaning of the data exchanged can be unambiguously understood by both sender and receiver because both parties have a shared vocabulary.

CEDAR uses architecture standards like FHIR and terminology standards such as RxNorm, SNOMED CT, MeSH, and others to support syntactic and semantic interoperability. FHIR's focus on health data and its basis on widespread internet standards make it a good fit for CEDAR's goal of improving access to PCOR and other research findings.

To represent and share information about indexed Artifacts, the CEDAR API uses FHIR's Citation Resource. The Citation Resource is still at a draft maturity level, which presents both challenges and opportunities. As a draft Resource, the Citation is likely to evolve based on input from the FHIR community, and changes may require the CEDAR RI to update its representation of the Citation. As an early adopter of this Resource, however, the CEDAR project can provide feedback and help shape future directions. Over the course of development, MITRE has participated in HL7 Connectathons to demonstrate data exchange using the Citation Resource. As a result of this participation, MITRE has both refined its use of the Citation Resource and recommended changes for future versions of the resource.

To address semantic interoperability, the CEDAR RI leverages clinical synonyms and standard vocabularies. As detailed in this report, CEDAR uses Artifact keywords to identify related concepts via the UMLS Metathesaurus.

Finally, using standards will also help developers build applications that leverage CEDAR and integrate CEDAR with existing applications by providing a clear framework for interoperability supported by common data standards.

Application of FAIR Guiding Principles

During the third of four FAIR assessments conducted over the course of the project, MITRE reviewed scores provided for each of the CEPI repositories and CEDAR API assessments. The team noted there was opportunity to update the functionality of CEDAR to better align with and improve the FAIRness of all CEPI repositories for criterion A2.1, "Metadata remain available if the data become unavailable." MITRE decided to update the CEDAR RI to retain Artifact metadata in the CEDAR Datastore, even after the Artifact from a repository is no longer available. To support this effort, MITRE created a new Artifact status in CEDAR called "retracted." When CEDAR reindexes CEPI repositories and detects that an Artifact is no longer available, CEDAR indexing marks the Artifact as "retracted," but retains its metadata. This update to CEDAR provides better adherence to the FAIR Guiding Principles and directly improves the FAIRness score for each CEPI repository for criterion A2.1.

Development of a Client Application User Interface

The API provides flexibility in where and how CEDAR can be used, but it is difficult to demonstrate to project partners and potential end users. As part of the development of CEDAR, MITRE created a client web application—CEDAR User Interface (CEDAR UI)—with two user interfaces. The CEDAR UI can be launched within a SMART on FHIR context or as a

standalone application. These different application contexts support two different use cases: a clinical use case and a research-oriented use case.

For the clinical use case, the CEDAR UI SMART on FHIR interface provides a notional example of how CEDAR could be integrated with an EHR system or patient portal. For the research-oriented use case, CEDAR UI offers a search interface with a variety of filters. This version of CEDAR UI also allows a user to locate CEDAR Artifacts by browsing the MeSH hierarchy. When considered together, the SMART on FHIR context and standalone application reinforce that the CEDAR API can support many use cases with potentially varied user interfaces.

Developing the user-facing CEDAR UI application alongside the RI conferred several additional benefits:

- It enabled MITRE to demonstrate CEDAR during the development process and get feedback from a wide array of project partners and potential end users. An iterative development process, where feedback was integrated early and often, was critical to ensuring that the CEDAR met its goals.
- It allowed MITRE to test the CEDAR API internally for functionality, usability, and correctness. Throughout development, MITRE kept the capabilities of CEDAR API and CEDAR UI in lockstep; when the team added new functionality to CEDAR API, the team exposed this functionality in CEDAR UI shortly thereafter. This practice allowed the MITRE team to identify, triage, and address RI errors or flaws (i.e., “software bugs”).
- It supported piloting the CEDAR API by serving as a reference implementation.

Test and Iteration of CEDAR API

MITRE conducted beta testing between April 6 and May 16, 2022, to: 1) dry-run a think-aloud protocol planned for the pilot task and 2) conduct an initial test of the pilot partner’s application and CEDAR API to identify and resolve any critical incidents prior to going live with the pilot. Beta testers included MITRE and AHRQ clinical subject matter experts (SMEs), MITRE researchers, and AAFP researchers.

The beta testers identified a total of 34 issues. MITRE subsequently assigned each issue a priority of high, medium, or low and determined whether the issue was related to the pilot application or the API.

MITRE collaboratively reviewed 13 issues pertaining to the pilot application with AAFP prior to the start of the pilot. These items included smaller changes such as user interaction enhancements, application copy changes, and error handling adjustments as well as larger requests, like incorporating date filtering. AAFP addressed eight of the 13 requests before the pilot began and retained the remaining five for potential future review. The primary driver for AAFP not implementing additional changes was AAFP development staff time.

Twenty-one issues from beta testing were related to the CEDAR API, some of which were identified as duplicates or closely related. Most of the issues (19) concerned the quantity or relevancy of search results returned by API. Flagged searches also covered cases where no artifacts were returned, but users expected AHRQ resources to be surfaced by CEDAR. For each flagged search, MITRE investigated if the API was functioning as intended or if there was an issue with specific API logic. For cases in which the API was operating as designed, the team initiated broader discussion on whether modifications to the design were warranted or desirable. For cases with logical issues, the team tracked, initiated, and completed development tasks to address the issues. A summarized and aggregated list of the issues relevant to the API are included in Appendix B.

Assessing FAIRness

One of the objectives of CEDAR was to make the CEPI repositories and the evidence they house more FAIR. To meet this project objective, MITRE sought to measure the baseline level of CEPI evidence adherence to the FAIR Guiding Principles and to document changes made over the course of the project and API development.

In the environmental scan, the MITRE team evaluated existing FAIR assessment tools and their applicability to CEDAR content. MITRE used the Research Data Alliance's (RDA's) work evaluating 12 existing FAIR assessment tools as its starting point. MITRE conducted a separate evaluation of the 12 existing FAIR assessment tools to determine suitability for use in the CEDAR project. At the conclusion of the assessment, MITRE determined that none of the referenced tools would adequately assess the FAIRness of the CEPI repositories, primarily because the existing tools assessed underlying datasets, not entire repositories.

To accommodate the need to assess FAIRness, MITRE created a new tool to assess repository FAIRness, known as the CEDAR FAIR Tool (C-FAIR). C-FAIR adapted the FAIR Guiding Principles to assess the CEPI repositories themselves instead of the individual evidence artifacts within the repositories. MITRE determined that, for purposes of CEDAR, it would be more effective to assess FAIRness of a CEPI repository as a collection of digital objects to provide a holistic view of a repository's FAIRness. C-FAIR supported this method of FAIRness assessment by analyzing the metadata associated with a repository's collection of digital objects. C-FAIR development occurred in parallel with CEDAR API development, allowing for multiple assessments to capture the FAIRness of new and developing API functionality providing access to digital objects' metadata. Additionally, MITRE created a scoring system for each of the newly adapted C-FAIR criteria.

MITRE used C-FAIR to assess the CEPI repositories four times. MITRE conducted the first assessment in early June 2021 as a trial of both the tool and an initial assessment of the repositories' FAIRness. MITRE assessed repositories using six findability criteria that totaled a possible findability score of 18 points, and three accessibility, interoperability, and findability

criterion for an overall potential score of 45 points. MITRE subsequently modified C-FAIR based on AHRQ and internal feedback to consolidate two of the findability criteria into one. MITRE also removed the findability criterion F4.1, “Artifacts include the associated (meta)data identifiers,” because the team determined this criterion related too closely to interoperability (specifically I3.1, “Metadata include qualified references to associated metadata”). The C-FAIR tool’s criteria ultimately included five findability criteria that totaled a possible findability score of 15 points, and three accessibility, interoperability, and findability criteria each for an overall potential score of 42 points.

MITRE conducted a second assessment between the end of June 2021 and early July 2021. MITRE then further revised C-FAIR to reduce dependence on input from the repository stewards and enable independent assessments of the CEPI repositories. Additional updates to the description of criteria ensured the objectives and framing were clear and appropriate. For example, the team modified the name and description for Criterion A1.1 between Assessment 1 and Assessment 2 to reflect that metadata retrieval should be open and non-proprietary.

In November 2021, MITRE conducted Assessment 3. This assessment accounted for significant CEDAR development updates. MITRE also modified the C-FAIR criteria to incorporate aspects of the FHIR Citation Resource within its scoring system. The Citation Resource aligns with the mission of increasing FAIRness because the Citation Resource defines an extensive set of data elements in its resource structure that support the FAIR Guiding Principles. Primarily, the Citation Resource contains a “citedArtifact” element to clearly distinguish data about the cited artifact (metadata of the cited artifact) from data about the citation (metadata of the Citation).⁹ Assessment 3 subsequently assessed how using the CEDAR API to index artifacts from CEPI repositories impacted those repositories’ FAIRness. MITRE conducted a final assessment, Assessment 4, in September 2022, after the conclusion of the project’s pilot test.

By conducting four assessments, MITRE has been able to demonstrate CEDAR’s impact on increasing repository FAIRness. To date, most repositories saw an increase in FAIRness, and most noticeably after the introduction of the CEDAR API between Assessments 2 and 3. Specifically, MITRE noted the following findings of interest:

- **Clinical Decision Support (CDS) Connect:** CDS Connect exhibited its highest level of FAIRness in Assessments 3 and 4, after the introduction of the CEDAR API. The API facilitated identification of the globally unique identifiers associated with CDS Connect artifacts as well as indexing of CDS Connect’s rich metadata.
- **Effective Health Care Program (EHC):** EHC exhibited its highest level of FAIRness in Assessments 3 and 4 after the introduction of the CEDAR API. MITRE found a slight decrease in FAIRness between Assessment 1 and 2 because of revisions to the tool’s findability criteria related to metadata, as not all of EHC’s artifacts contained metadata

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

elements. In addition, MITRE performed the second assessment without the input of repository steward knowledge and required assessment based only on what was externally available to the public. However, with the introduction of the CEDAR API as well as adjustments to the EHC architecture including the introduction of a data feed for CEDAR’s indexing use, EHC’s FAIRness score later increased.

- **Evidence-Based Practice Centers (EPC):** MITRE did not score EPC during the first two assessments because of ambiguity surrounding its identity as a standalone repository separate from EHC. EPC performed moderately well in its overall evaluation of FAIRness during Assessment 3 and performed even better in Assessment 4.
- **Systematic Review Data Repository (SRDR):** SRDR exhibited its highest level of FAIRness in Assessment 3 and Assessment 4 after the introduction of the CEDAR API and update to SRDR+. Through the API functionality, MITRE determined that there are key provenance elements within the repository’s digital artifacts’ metadata that align with the FHIR Citation Resource and its key elements. In addition, a data use license is provided when asked to register for the new iteration of SRDR, SRDR+, which supports “accessibility” in that it explains how data can be accessed and used.
- **U.S. Preventive Services Task Force (USPSTF):** USPSTF exhibited its highest level of FAIRness in Assessments 3 and 4 after the introduction of the CEDAR API. All four FAIR facets (findability, accessibility, interoperability, and reusability) improved when the CEDAR API was used to index and provide digital artifacts from the USPSTF repository. After the first assessment, MITRE learned that USPSTF uses a unique identifier number within its repository database in lieu of a durable, globally unique identifier, resulting in a decreased FAIRness score between Assessment 1 and 2.¹⁰
- **CEDAR API:** The CEDAR API itself was also not scored during Assessments 1 or 2 because the API had not yet been deployed. The Assessment 4 score of 39 is high in overall FAIRness due to the CEDAR API and C-FAIR Tool’s alignment with the FHIR Citation Resource and additional FHIR API functionality.

Table 1 presents the total scores for each repository in each of the first three assessments.

Table 1. C-FAIR Tool Assessment Results

CEPI Repository Total Score	Assessment 1	Assessment 2	Assessment 3	Assessment 4
CDS Connect	21	35	39	42
EHC	16	14	32	38
SRDR	15	31	33	33
USPSTF	21	14	37	42
EPC	N/A	N/A	29	38
CEDAR API	N/A	N/A	36	39

¹⁰ The USPSTF repository uses a unique number within the context of its repository database, so the identifier is not globally unique as FAIR Guiding Principles recommend.

Security Review

At various times and for various purposes throughout the course of the project, the CEDAR code was examined and assessed for security purposes. In fall 2021, MITRE requested an internal security review of the code, which was a manual secure code review of the CEDAR code. Subsequently, in spring 2022 and in preparation for changes in AHRQ's internal technical infrastructure, AHRQ conducted an external automated security scan run by a tool to identify any gaps or flaws in the software. Security reviews are important for systems that will be deployed to reduce the risk of cyberattacks, as well as to ensure that sensitive information is protected.

Technical Documentation

Over the course of the period of performance, in conjunction with the development of the CEDAR RI, the project team wrote and iterated a series of documents in support of the usage of the service. This technical documentation includes webpages explaining how to get started with the API, an interactive API exploration tool, and an installation guide.

Pilot

The CEDAR RI's purpose is to disseminate evidence from multiple sources in one location and to increase the FAIRness of the CEPI repositories. MITRE and AAFP tested CEDAR in a real-world setting to assess the feasibility of its implementation by a third-party entity, as well as to evaluate the utility of the tool for end users of CEPI's evidence.

MITRE partnered with AAFP, a medical organization focused on family doctors and primary healthcare, to pilot the RI because of the association's ability to develop and host a client application within which to integrate the CEDAR API; further, many of AAFP's members and staff actively use AHRQ evidence in day-to-day activities for a wide variety of purposes, including research, quality improvement, guideline development, and clinical practice, enabling recruitment of AAFP members representing different types of end users for pilot testing.

AAFP implemented the CEDAR API and developed an application it named "CEDAR Search." AAFP hosted CEDAR Search on its website, providing access to MITRE, AHRQ CEDAR team members, and the AAFP pilot testers. The AAFP Institutional Review Board (IRB) evaluated and approved the initiative prior to participant recruitment. AAFP conducted pilot testing asynchronously with testers who were oriented to the application and in real-time "think-aloud" sessions in which testers shared their screens and talked through their experience of using the application. MITRE documented qualitative feedback during think-aloud sessions. Pilot testers provided feedback using assessments hosted on the Qualtrics platform. MITRE and AAFP collected quantitative data using application logging capabilities as well as measured the time of each platform's ability to query and return results.

A complete overview and discussion of the CEDAR pilot and pilot results is available in the AHRQ CEDAR Final Pilot Report.¹¹

Outreach

CEDAR engaged stakeholders in its work through discussions and meetings to clarify stakeholder needs, perceptions, and expectations about how CEPI resources and programs could be used to access evidence-based research and findings. MITRE's outreach emphasized strategy development, tactical planning, and execution, in addition to coordinating with pilot-planning and development activities. Its overarching goal was to drive stakeholder interest, energy, and involvement during the development and establishment of CEDAR. In addition, the team shared information gathered from stakeholder and end-user input with the development team, so that this feedback could be applied to current and future iterations of the CEDAR RI.

Key findings from the outreach were:

- Stakeholders and end users expressed enthusiasm for CEDAR.
- AHRQ offers evidence that is highly trusted and that engenders high confidence.
- Stakeholders and end users expressed robust support for the concept of a single point of entry to a variety of CEPI repositories and recommended other AHRQ resources be indexed into CEDAR to make the service more robust.

A complete overview and discussion of outreach and engagement is available in the AHRQ CEDAR Stakeholder Outreach Final Report.¹²

Project Management

Operational Leadership

A leadership team managed the CEDAR project and its respective tasking on a day-to-day basis. This team included a Project Leader, a Deputy Project Leader, a Technical Lead, and Task Leads for the Pilot and Outreach tasks. The leadership team met biweekly throughout the period of performance to ensure collaboration and communication across tasks, and to address as a team any issues or questions that arose. Additional MITRE leadership, including a Program Manager, Department Manager, and Division and Department Chief Engineers provided oversight and

¹¹ AHRQ CEDAR: Final Pilot Report 2022. (Prepared by Centers for Medicare & Medicaid Services Alliance to Modernize Healthcare (The Health FFRDC) under Contract No. 75FCMC18D0047.) AHRQ Publication [Pending]. Rockville, MD: Agency for Healthcare Research and Quality. September 2022.

¹² AHRQ CEDAR: Final Outreach Report 2022. (Prepared by Centers for Medicare & Medicaid Services Alliance to Modernize Healthcare (The Health FFRDC) under Contract No. 75FCMC18D0047.) AHRQ Publication No. [Pending]. Rockville, MD: Agency for Healthcare Research and Quality. September 2022.

management through a weekly touch-base, as well as more extensive program check-ins and ad hoc outreach.

The team measured progress on project work during fortnightly Agile “sprints,” with activities tracked in Jira. The team conducted planning meetings on the first day of a new sprint; AHRQ leadership and staff with a direct interest in the project (e.g., repository stewards) attended a review meeting at the conclusion of each 2-week sprint.

Internal and External SME Engagement

The MITRE project team engaged frequently with internal and external SMEs throughout the course of the project—not merely in the context of the stakeholder outreach task, but also in the scope of development and pilot activities. MITRE consulted with multiple experts, including:

- CEPI repository stewards and technical staff to inform understanding of both repository technical specifications and end-user needs.
- MITRE project leaders and experts in clinical data management working on tasks incorporating FAIR Guiding Principles to explore assessment tools, understanding of the principles, and application of the principles in practice.
- MITRE clinical and research SMEs with expertise in PCOR to understand nomenclature, practices, and end-user needs.
- Software developers and health information technology experts internal and external to MITRE to understand similar and complementary initiatives, collaborate on testing and at connectathons, and explore relevant standards advancement.
- Experts in the health and clinical research industries to highlight and create awareness of MITRE’s support to AHRQ on the [CEDAR](#) project and [CDS Connect](#).
- Academic institutions and public health experts to provide a demonstration of CEDAR, talk about potential pilot opportunities, and receive real-time feedback and input.

Lessons Learned

MITRE noted several lessons learned during this project that can inform overall management and operations of the CEDAR project. Going forward, MITRE invites AHRQ to consider the following concepts:

- Communications about CEDAR and its progress should occur early and often with AHRQ team members, especially leadership. MITRE found collaboration with the AHRQ team robust and insightful, and that it ensured the project moved forward appropriately.
- AHRQ should engage in early planning for pilot testing, as the pilot partner will need to be able to either develop a client application in which to implement the API or have an application already at hand.

Category of Recommendation	Recommendation Text
Reference Implementation - Development	Include additional search functionality for the CEDAR RI (e.g., enable search results that also surface or suggest related artifacts.)
Reference Implementation - Development	Display content that both underlies and derives from a search result so that end users can see the landscape of evidence related to a selected search result.

Appendix A. Status of Recommendations from the Environmental Scan

Table 3. Recommendations from Environmental Scan and Status

Recommendation	Near- or Long-Term	Status
Develop FAIR assessment criteria aligned to the PCOR domain to assess the CEPI repositories.	Near-Term	Completed with changes. FAIR assessment criteria were developed that aligned to health evidence generally and specific to evaluating the FAIRness of repositories, not data artifacts.
Make FAIR assessment criteria could be made available to other repositories interested in aligning with CEDAR so those repositories can self-assess FAIRness.	Near-Term	In progress. The C-FAIR tool may be made accessible to any data steward with inclusion on the CEDAR landing page upon conclusion of the project period.
Leverage the stakeholder community to understand different needs and pain points associated with the use of the CEPI repositories and web-based data repositories generally to enhance the CEDAR RI.	Near-Term/Long-Term	Completed/In progress. Multiple activities involving end user communities were completed during the project and feedback and input used to inform the development of CEDAR. This should be an ongoing task to continually socialize and iterate upon CEDAR.
Investigate if there are any technological barriers for clinicians serving specific populations that would impact ease of use of the CEDAR RI.	Near-Term	In progress. This has been incorporated into stakeholder outreach and pilot testing, but more work could be done to explore feasibility and utility of integrating CEDAR into EHR systems and point of care.
Explore alternatives for ingestion of data from repositories that do not currently offer APIs so that the CEDAR RI does not need to crawl websites to index the contents.	Near-Term	Completed for the repositories indexed in CEDAR.
Future repositories and/or versions of CEPI repositories should be contractually required to include RESTful API(s), considering FHIR or other standards as appropriate, to enable smooth connection and interoperability with CEDAR. In the alternative, AHRQ could require repositories to follow a very specific, CEDAR-recommended API standard.	Long-Term	Not started. CEPI is still in the testing phase of CEDAR. Stakeholder and pilot tester feedback has enforced the idea that additional AHRQ data sources would be welcome additions to the information that CEDAR already indexes, so this recommendation should continue to be considered.
Alignment with or ability to transform to a common data model, such as FHIR, supports CEDAR integration. Providing clear guidance and alternatives to potential integrators can assist in facilitating self-integration and evaluation of integration potential.	Long-Term	In progress. CEDAR technical documentation offers some discussion of guidance but could be more robust and a future area of development.

Recommendation	Near- or Long-Term	Status
<p>Research PCOR repositories not currently included in the initial RI but that could be candidates for lessons learned in data stewardship, data linkage, and cross-pollination, as well as for future integration with the CEDAR RI. (This overlaps with ongoing stakeholder engagement recommendations).</p>	<p>Long-Term</p>	<p>In progress. This research was conducted in the environmental scan and throughout the project period of performance stakeholders, pilot testers, and project team members surfaced and suggested other data sources of interest. Most end users suggested expanding the content that CEDAR indexes, but MITRE’s recommendation would be to initially scale CEDAR to include additional AHRQ data sources only.</p>
<p>Extend repository support beyond the CEPI repositories or those specific to PCOR into domains that are generally outcomes related or more broadly health related to continually enhance the robustness of the CEDAR RI.</p>	<p>Long-Term</p>	<p>Not started. Any expansion should first index additional AHRQ resources and data sources.</p>
<p>Coordinate with AHRQ’s Federal partners on PCOR-related strategies to coordinate and contribute to plans for the ongoing and future development of the overall PCOR and health domain data exchange infrastructure.</p>	<p>Both</p>	<p>Not started. A pilot with another agency and/or sharing the C-FAIR tool in addition with a demonstration of CEDAR may be interesting starting points for additional collaboration beyond what is already done.</p>
<p>Plan alignment with other existing technology efforts to provide health information to patients, such as the FHIR-based APIs intended to enable patients to send their health information to third-party applications of their choice and determine how CEDAR might play a role in supplementing health information with patient educational materials and other information useful to patients in managing their health.</p>	<p>Both</p>	<p>Not started. This idea was considered as a use case for the initial CEDAR pilot, but a different use case was selected instead. This may be a use case that can be revisited for future pilot testing since the requirements for the Patient Access API will be effective [2023?].</p>
<p>To align with FAIR Guiding Principles, CEPI repositories should include permanent identifiers in any offered APIs that will allow CEDAR to maintain an enduring link to the source CEPI repository.</p>	<p>Both</p>	<p>Not started/not in CEDAR scope.</p>
<p>Consider the development of an easy pathway to self-integration for external repositories that want to integrate with CEDAR rather than implementing additional integrations in the future. Consider concurrently the installation of a gateway or checkpoint to integration to address any potential security risks.</p>	<p>Both</p>	<p>Not started.</p>

Appendix B. Beta Test API Findings

Table 4. Aggregated List of Summary Beta Test Findings Relevant to the API

Issue Identified	Priority	Resolution
Additional context or definitions needed for artifact categories	Low	No action at this time. CEDAR relies on the artifact types assigned by repository.
Clinical trial results and published research should be included in CEDAR (additional resources)	Low / Enhancement	No action at this time. Future discussion with AHRQ about scope of CEDAR indexed content.
Research protocols should be included in CEDAR (additional resources)	Low	No action/resolved. Research protocol is an existing artifact type so search results can be filtered to show only research protocols.
Additional search functionality (e.g., the ability to use “and” and “or”) would be helpful	Low	Resolved. Added instructions on how to use this search functionality.
Using the API functionality to email an artifact resulted in the wrong artifact sent	High	Resolved.
Suggestion to add ability to download citations	Low / Enhancement	Open.
Result contents not useful	Low / Repository	In progress. This is not an API issue, but action to emphasize of the contents of the CEPI resources indexed in API documentation.
Downloads should be able to be done in fewer steps	Low / Enhancement	Open.
Additional resources should generally be included to be comparable to PubMed	Low / Enhancement	In progress. Address expectations with additional information in API documentation about scope of CEDAR indexing; discuss over time with AHRQ potential to scale to index additional AHRQ information.
Specific search terms and addition of others can seriously impact results	Low / Enhancement	Open. May be resolved by use of binary AND/OR logic in this search. AND/OR implemented; will monitor impact and awareness of the functionality.

Issue Identified	Priority	Resolution
Select multiple results	Low / Wish list	Open/unresolved. While capability added to download entire search results to CSV, do not yet have the ability to select specific results for download. Will not happen within the pilot.
SRDR requires a secondary login	Low / Wish list	Resolved. Unable to reproduce exact issue. Can consider adding additional information to API documentation to alert users there may be a requirement for secondary logins in some instances.
Rank keywords (e.g., more than alphabetical order)	Low / Enhancement	Open.

Appendix C. Abbreviations and Acronyms

Term	Definition
AAFP	American Academy of Family Physicians
AHRQ	Agency for Healthcare Research and Quality
API	application programming interface
CDS	clinical decision support
CEDAR	CEPI Evidence Discovery And Retrieval project (AHRQ)
CEDAR UI	CEDAR User Interface
CEPI	Center for Evidence and Practice Improvement (AHRQ)
C-FAIR	CEDAR FAIR Tool
EHC	Effective Health Care Program
EPC	Evidence-based Practice Centers
FAIR	findable, accessible, interoperable, and reusable (guiding principles)
FFRDC	Federally Funded Research and Development Center
FHIR	Fast Healthcare Interoperability Resources
HL7	Health Level Seven (clinical standards and messaging formats)
HTTP	Hypertext Transfer Protocol
IP	Internet Protocol
IRB	Institutional Review Board
JSON	JavaScript Object Notation
MeSH	Medical Subject Heading
NGC	National Guideline Clearinghouse
PCOR	patient-centered outcomes research
PDF	Portable Document Format (file type)

Term	Definition
RDA	Research Data Alliance
REST	REpresentational State Transfer
RI	Reference Implementation
SME	subject matter expert
SNOMED	Systematized Nomenclature of Medicine
SNOMED CT	SNOMED Clinical Terms
SRDR	Systematic Review Data Repository
SRDR+	Systematic Review Data Repository Plus
UI	User Interface
UMLS	Unified Medical Language System (National Library of Medicine)
USPSTF	U.S. Preventive Services Task Force
VPAT	Voluntary Product Accessibility Template documentation
XML	Extensible Markup Language