FAIR Access to Patient-Centered Outcomes Research in AHRQ CEPI Repositories: An Environmental Scan to Inform the Development of CEDAR

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Executive Summary

To improve our healthcare system nationwide, it is critical that clinicians have access to evidence-based research to make the best decisions while balancing quality with cost. The Agency for Healthcare Research and Quality (AHRQ), the lead Federal agency charged with improving the safety and quality of America's healthcare system, disseminates patient-centered outcomes research (PCOR) evidence and advances clinical decision support (CDS). AHRQ develops the knowledge, tools, and data needed to improve the healthcare system and help Americans, healthcare professionals, and policymakers make informed health decisions. In its development of these tools and data, AHRQ identified a need for clinicians to rapidly and efficiently access evidence from multiple PCOR repositories at one time to further AHRQ's dissemination of PCOR evidence and findings.

To this end, AHRQ and its Center for Evidence and Practice Improvement (CEPI) requested the assistance of the Centers for Medicare & Medicaid Services' 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). This RI will demonstrate the use of a standards-based application programming interface (API) to find, access, and use PCOR evidence from multiple existing repositories. The RI will align with the FAIR (Findable, Accessible, Interoperable, and Reusable) Data Principles for scientific data stewardship.[1, 2]

This environmental scan is the first step in the development of the RI. It is intended to increase understanding and knowledge of multiple PCOR subject matter areas as well as reveal gaps in knowledge, infrastructure, and technology, therefore allowing the RI to be tailored to these needs and gaps. The scan first examined the technical specifications of the following CEPI repositories housing PCOR data:

- Effective Health Care Program
- Systematic Review Data Repository™
- National Guideline Clearinghouse™
- U.S. Preventive Service Task Force Recommendations
- CDS Connect

In addition, the scan reviewed FAIR Data Principles and existing tools assessing FAIRness, other PCOR and health-related repositories, and relevant health IT standards. Finally, the scan studied relevant stakeholders to ensure that the RI will meet the needs of the user community.

Based on these sources, this document identifies technical and non-technical risks to successful RI development and repository integration into the CEDAR RI. Overall, the scan and risk review found that integration with the CEDAR RI will be simplified when a repository offers an API

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1 AHRQ evidence-based Care Transformation Support (ACTS), Overview, https://digital.ahrq.gov/acts.

2 Work underway pursuant to ACTS is also contributing to the advancement of FAIR Data Principles and the recognition that to best facilitate the dissemination of evidence and findings, data must be stewarded in a way that ensures it can be found by both humans and machines. AHRQ evidence-based Care Transformation Support (ACTS) Initiative, A Roadmap for AHRQ and Other Stakeholders, AMIA Annual Meeting (November 18, 2019), https://digital.ahrq.gov/sites/default/files/docs/page/acts-townhall-amia-2019.pdf.

and uses a common metadata format; without an API, there is a risk that integration will be more fragile, as changes in the underlying repository, such as link identification, can break the indexing in the RI.

Even if repositories have APIs, the scan found that the technical specification, content, content identification, and API usage across the CEPI repositories varies, which in some cases may complicate, but which will ultimately not be a bar to, integration. To mitigate these issues, the CEDAR RI will likely need to regularly examine integration as development progresses. Furthermore, in the future, the repositories should consider these issues as they are developed to aid future integration.

Based on the above considerations, this scan provides recommendations to advance successful RI development and repository integration. These recommendations include:

1. Develop FAIR assessment criteria aligned to the PCOR domain to assess the AHRQ CEPI repositories.
2. Leverage the stakeholder community to understand different needs and pain points to enhance the CEDAR RI.
3. Investigate technological barriers for clinicians serving specific populations that would impact ease of use of the CEDAR RI.
4. Explore estimated cost for repositories without APIs to periodically aggregate their information for CEDAR RI ingestion so that the CEDAR RI does not need to crawl their websites.
5. Future repositories and/or versions of AHRQ CEPI repositories should be contractually required to include RESTful[3] API(s), considering Fast Healthcare Interoperability Resource (FHIR®) or other standards as appropriate, to enable smooth connection and interoperation with CEDAR. In the alternative, AHRQ could consider requiring repositories to follow a very specific, CEDAR-recommended API standard.
6. Scale and continue to develop the CEDAR RI by researching and evaluating PCOR repositories not part of the RI.
7. Extend repository support beyond the CEPI repositories or those specific to PCOR into domains that are generally outcomes-related and more broadly health-related to continually enhance the robustness of the CEDAR RI.
8. Collaborate with AHRQ's Federal partners, including on other agencies' PCOR-related strategies, to coordinate and contribute to plans for the ongoing and future development of the overall PCOR and health domain data strategy and infrastructure.
9. 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,[4] and determine how CEDAR

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[3] "REST" is an acronym for Representational State Transfer and is a software architectural style commonly used to create interactive web applications.

[4] Final Rule, 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program, 85 FR 47099 (August 4, 2020), and Final Rule, Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Interoperability and Patient Access, 85 FR 25510 (May 1, 2020).

might play a role in supplementing health information with patient educational materials and other information useful to patients in managing their health.

10. To align with FAIR Data Principles, AHRQ CEPI repositories should include permanent identifiers in any offered APIs that will allow CEDAR to maintain an enduring link to the source CEPI repository.
11. 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.

In the next phase of the project, the CEDAR RI will be developed in conjunction with the insights and recommendations developed from this environmental scan. Stakeholder outreach will be conducted concurrently to further inform development. Finally, once the RI reaches production stage, the CEDAR RI will be piloted in a representative end user environment.

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1 Introduction

1.1 Background

The Patient Protection and Affordable Care Act (ACA) of 2010 emphasized the importance of patient-centered outcomes research (PCOR). The ACA mandated that the Agency for Healthcare Research and Quality (AHRQ) invest in the dissemination of PCOR findings.[5] For those purposes, PCOR findings are defined as the "comparison of the impact of two or more preventive, diagnostic, treatment, or healthcare delivery approaches on health outcomes, including those that are meaningful to patients."[6]

AHRQ disseminates PCOR findings to stakeholders and end users, including providers, health systems, patients, payers, and policymakers. To facilitate this dissemination, AHRQ develops electronic means to transfer research findings, maintains publicly available databases of government-funded scientific study data, and trains researchers in PCOR methods.

AHRQ and its Center for Evidence and Practice Improvement (CEPI) requested the assistance of the Centers for Medicare & Medicaid Services' 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). CEPI sought the Health FFRDC's assistance to further its dissemination of PCOR evidence and findings through clinical decision support (CDS) after complementary efforts highlighted the need to do so.[7] The RI will align with the FAIR (Findable, Accessible, Interoperable, and Reusable) Data Principles for scientific data stewardship.[8]

AHRQ is committed to increasing the FAIRness of the AHRQ CEPI PCOR repositories, developing processes to connect data sources, recommending adoption of Health Level 7 (HL7®) standards related to PCOR evidence dissemination, and developing free, open-source software. Achieving these commitments can improve access to PCOR evidence and findings, which can, among other benefits, facilitate shared decision making by clinicians and patients. For example, a clinician who can more easily find the latest evidence about effective options for a condition that she treats will be in a better position to have informed discussions with her patients. Similarly, an electronic health record (EHR) developer implementing CDS functionality can help make evidence-based decision making more systematic by using interoperable and reusable CDS artifacts. These types of downstream outcomes are part of the longer-term vision for CEDAR. This environmental scan is the first step in the process of developing the CEDAR RI and its accompanying tools to disseminate and implement PCOR in clinical practice through CDS.

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5 Section 6301 of the Patient Protection and Affordable Care Act of 2010, PL 111-148.

6 AHRQ, Frequently Asked Questions About the Selection Process for AHRQ Dissemination and Implementation Initiative, available at https://www.ahrq.gov/pcor/ahrq-dissemination-and-implementation-initiative/pcortf-faq.html.

7 AHRQ evidence-based Care Transformation Support (ACTS), Overview, https://digital.ahrq.gov/acts.

8 Work underway pursuant to ACTS is also contributing to the advancement of FAIR Data Principles and the recognition that to best facilitate the dissemination of evidence and findings, data must be stewarded in a way that ensures it can be found by both humans and machines. AHRQ evidence-based Care Transformation Support (ACTS) Initiative, A Roadmap for AHRQ and Other Stakeholders, AMIA Annual Meeting (November 18, 2019), https://digital.ahrq.gov/sites/default/files/docs/page/acts-townhall-amia-2019.pdf.

1.2 Purpose

The purpose of this survey and evaluation of the PCOR landscape is to inform the RI by increasing understanding and knowledge of multiple PCOR subject matter areas, as well as reveal gaps in knowledge, infrastructure, and technology. The CEDAR project can use the findings from this environmental scan to develop an RI that demonstrates how clinicians, patients, and other end users can more effectively obtain data helpful for healthcare decisions.

1.3 Scope

This environmental scan encompasses the following subject areas and assessment activities:

- Literature and web reviews
- Interviews and informational meetings
- Research into stakeholders interested in PCOR and related health information
- Review of other sources of PCOR, PCOR-related, and similar information and findings
- Review of FAIR Data Principles and tools for assessing adherence
- Review of health information technology (IT) standards available for use with the RI
- Analysis of technical specifications underlying each AHRQ CEPI PCOR repository intended for inclusion in the initial CEDAR RI, as well as any anticipated challenges to their integration into the RI
- Discussion of gaps that may impact development and implementation
- Findings and recommendations for current RI development and future opportunities for CEDAR

2 Methodology

The environmental scan relied on broad research of the PCOR evidence environment and leveraged a combination of tools as described in the following subsections. Methodology varied depending upon the type of information reviewed (e.g., technical specifications or scan of relevant stakeholders).

2.1 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 HL7®, Integrating the Healthcare Enterprise, and HealthIT.gov. Search terms varied according to research subject.

2.2 Informational Meetings

Informational meetings with an initial pool of subject matter experts[9] and stewards of AHRQ CEPI repositories[10] laid the groundwork for understanding the contents, end users, and technical specifications of each CEPI repository identified for inclusion in the CEDAR RI.

In addition to these informational meetings, other potential stakeholders likely to have an interest in PCOR, such as participants in the AHRQ ACTS Initiative, and their connection to the CEPI repositories, were identified for future outreach and engagement efforts.[11]

2.3 Review of Other Sources of PCOR Information

Other projects, repositories, and resources related to PCOR and health were evaluated as additional sources of PCOR evidence and findings that could be connected to CEDAR in the future. These resources are compiled and included in Appendix B, and include data repositories beyond those specifically intended for inclusion in the initial CEDAR RI.

2.4 Review of FAIR Data Principles

The CEDAR RI will increase the CEPI PCOR repositories' alignment to the FAIR Data Principles.[12] Available FAIR assessment tools were assessed for ability to evaluate the FAIRness of the CEPI repositories and the CEDAR RI. The tools were also evaluated to identify candidate criteria for the creation of a new tool for assessing the FAIRness of the CEPI repositories.

Appendix A provides the complete results of the independent review of FAIR assessment tools and details the development of a PCOR domain-specific FAIR assessment tool that will support the CEDAR RI, the AHRQ PCOR repositories, and future repositories.

2.5 Alignment with Health IT Standards

Alignment with health IT standards promotes scalability of the RI and expands the RI into a production-quality, sustainable application. By aligning with standards, the RI provides a clear set of expectations for repositories.

Health IT standards were identified for assessment for alignment with CEDAR, including Fast Healthcare Interoperability Resource (FHIR®) resources and implementation guides related to evidence-based medicine, FAIRness, and metadata. Standards were reviewed for relevance to CEDAR requirements and maturity, as measured by the FHIR implementation community.

Appendix C presents a comprehensive overview of relevant health IT standards, resources, and modules assessed during the environmental scan.

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9 AHRQ and the MITRE team identified subject matter experts and included individuals knowledgeable in FAIR Data Principles, HL7® standards, and clinical research stakeholder needs.

10 Appendix D contains a comprehensive overview of research findings regarding AHRQ CEPI repository stakeholders.

11 For purposes of this environmental scan, the term "stakeholder" includes stakeholders and end users. Stakeholder engagement will be ongoing throughout the project to continually inform RI development.

12 AHRQ, CEPI Evidence Discovery And Retrieval (CEDAR) Project, https://digital.ahrq.gov/ahrq-funded-projects/cepi-evidence-discovery-and-retrieval-cedar-project.

2.6 Assessment of AHRQ CEPI PCOR Repositories

This environmental scan evaluated AHRQ CEPI repositories intended for inclusion in the CEDAR RI. Evaluation sought to determine the repositories' underlying architecture, data models and data schemas, and APIs, as well as the best approach for integration with the CEDAR RI. This technical analysis represents the key elements of this environmental scan:

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

2.7 Identification of Risks

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.

2.8 Recommendations

Recommendations were developed based on research, CEDAR architecture needs, and identified risks. Recommendations were categorized as either near-term or long-term, based on feasibility and estimated timeframe for achievement.

3 AHRQ CEPI Repositories Review and Analysis

This document details the analysis of the following repositories:

- The Effective Health Care (EHC) Program website, which houses the Evidence-based Practice Center (EPC) Program evidence reports
- The Systematic Review Data Repository™ (SRDR), which houses the evidence data files from EPC evidence reports
- The National Guideline Clearinghouse™ (NGC)
- The U.S. Preventive Service Task Force (USPSTF)
- CDS Connect

This section describes the review and technical analysis of each repository. In general, integration with the CEDAR RI will ultimately be simplified when a repository offers an API and uses a common metadata format. Without an API, integration is more fragile. Table 3-1 presents an overview of the AHRQ CEPI PCOR repositories, while Appendix E provides a comprehensive crosswalk of characteristics of each repository, including the metadata employed by each.

Table 3-1. AHRQ CEPI PCOR Repository Overview

Repository Characteristic	EHC	SRDR	NGC[13]	USPSTF	CDS Connect
Description	Provides access to the best available evidence on outcomes and appropriateness of healthcare treatments, devices, and services	Supports the execution and sharing of underlying study data from systematic reviews and (in SRDR+) summary systematic review data	Database-driven website that provided information on clinical practice guidelines	Volunteer panel of experts developing evidence-based recommendations about clinical preventive services	Repository of Clinical Decision Support Artifacts
Purpose/Goal	Improve the quality of healthcare by providing the best available evidence on the outcomes, benefits and harms, and appropriateness of drugs, devices, and healthcare services, and by helping healthcare professionals and others make informed healthcare decisions[14]	Provide a collaborative, web-based repository of systematic review data[15]	Provided physicians and other healthcare professionals, healthcare providers, health plans, integrated delivery systems, purchasers, and others an accessible mechanism for obtaining objective, detailed information on clinical practice guidelines and to further their dissemination, implementation, and use[16]	Improve the health of all Americans by making evidence-based recommendations about clinical preventive services such as screenings, counseling services, and preventive medications[17]	To advance evidence into clinical practice through CDS and to make CDS more shareable, standards-based, and publicly available[18]
Product Type/Types of Information	Outcomes evidence and other related data (other data is expected to be retired in 2021)	Systematic review data including literature searches, initial citation screening (underlying data in separate in terms of infrastructure but is on EHC site) Data are anchored around key questions (design characteristics)	Clinical practice guidelines (meeting explicit criteria for inclusion and for which copyright permissions were obtained, if not in the public domain)	Recommendations for clinical preventive services	Standards-based clinical decision support artifacts in various levels of representation: semi-structured, structured, and executable; and best practices and lessons learned from implementation and pilot study

[13] As will be discussed in Section 3.3, NGC is a legacy system not currently maintained and currently unavailable due to budget cutbacks, so the description of NGC relates to the system when it was still online. AHRQ intends to restore NGC in the future.

[14] AHRQ, About the Effective Health Care Program, https://effectivehealthcare.ahrq.gov/about.

[15] AHRQ, Evidence-based Practice Center (EPC) Program Overview, https://www.ahrq.gov/research/findings/evidence-based-reports/overview/index.html and AHRQ, SRDR: Systematic Review Data Repository™, https://www.ahrq.gov/cpi/about/otherwebsites/srdr.ahrq.gov/index.html.

[16] AHRQ, About NGC and NQMC, https://www.ahrq.gov/gam/about/index.html.

[17] USPSTF, About the USPSTF, https://www.uspreventiveservicestaskforce.org/uspstf/about-uspstf.

[18] AHRQ, CDS Connect, Frequently Asked Questions, https://cds.ahrq.gov/cdsconnect/faq.

Repository Characteristic	EHC	SRDR	NGC[13]	USPSTF	CDS Connect
Users	Healthcare professionals, researchers, and a small subset of content for patients, which is expected to be retired in 2021	Researchers, systematic reviewers, and users of systematic reviews (clinicians, policymakers, and the public)	Clinicians (practitioners, educators, students) and medical librarians were the primary users when active	Healthcare providers, patients, general population	Clinicians, clinical informaticists, patients, CQL developers, and health IT vendors
Metadata	Yes; difficult to determine values	Yes, metadata is available	Yes, metadata is publicly available; however, the tool is no longer available	Yes, metadata is available	Defined in data dictionary
Defined Taxonomy	Undetermined	No	Yes, UMLS®, MeSH® and SNOMED-CT®	Yes	Yes, MeSH
API and Search Capabilities	Proprietary search functionality (no API)	Interface to create extraction, faceted search (based on medical conditions)	The repository used Solr as a search service	Yes, RESTful API with search parameters	CDS Connect API
Architecture including Other APIs	Drupal™ content management system (no API)	Two API versions (one FHIR-structured JSON)	Proprietary content management system	JSON-based REST architecture (XML deprecated)	Drupal; MERN; Authoring Tool API; FHIR Clinical Reasoning API
Integration or Intersection Between Other CEPI Repositories	SRDR and EPC		USPSTF	EPCs to develop research plans and literature reviews	Not specified
View/Download Content	Download PDF	View and download	View and download with appropriate permissions (when active)	Download PDF	Upload/download and view
Future Goals	Expanded search functionality and facets Prototype reporting and data visualization Potential to accommodate other programs beyond EPC	Hand off information to another system/CDS	Not specified	Not specified	Not specified

3.1 Effective Health Care Program

The AHRQ EHC Program's goal is to improve healthcare quality by enabling access to the best available evidence on outcomes and appropriateness of healthcare treatments, devices, and services.[19] This evidence is published in various "products" such as white papers, clinician and

[19] AHRQ, About the Effective Health Care Program, available at https://effectivehealthcare.ahrq.gov/about.

consumer summaries,[20] and evidence reports (e.g., systematic reviews).[21] This information can assist end users, such as clinicians, in making informed patient care decisions. The EHC Program website includes multiple projects to further its goals, including the Evidence-based Practice Center (EPC Program®, although not all EHC Program projects are active.[22] All reports developed by the EPC Program, except those for the AHRQ Technology Assessment Program and USPSTF, are housed on the EHC Program website, and comprise the entirety of the most current content on the EHC website. EPCs are academic and other research institutions contracted by AHRQ to evaluate and summarize healthcare evidence.

3.1.1 Technical Specifications

Due to the proprietary nature of the tools used to manage the repository, review of the EHC Program's repository was limited to an examination of the public website and an interview with the Federal and contractor team responsible for stewarding the website. Without full access to the repository tools, the discussion of the repository's technical architecture information is constrained.

3.1.1.1 Architecture

The EHC Program website provides access to products via version 7 of the open-source Drupal content management system (CMS),[23] now under migration to version 9.[24] In addition to this version migration, other potential changes to the EHC website are under consideration, including development of several prototypes for new ways to display reports using visualizations and new filters for search results.[25]

3.1.1.2 Data Sources

The primary source of content for the EHC Program's website is the EPC Program; all recent content comes from this program.[26] Many of the other EHC Program projects from which content was previously sourced are no longer supported, such as the Eisenberg Center for Clinical Decisions and Communication Science and the Centers for Education and Research on Therapeutics.[27]

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20 Clinician and consumer summaries are anticipated to be retired in 2021. Repository Steward/Web Team Informational Meeting, Effective Health Care Program, February 12, 2021.

21 https://effectivehealthcare.ahrq.gov/products.

22 AHRQ, Effective Health Care Program History, available at https://effectivehealthcare.ahrq.gov/about/history.

23 Repository Steward Interview and Informational Meeting, Effective Health Care Program, October 22, 2020.

24 Id; Repository Steward/Web Team Informational Meeting, Effective Health Care Program, February 12, 2021.

25 Repository Steward Interview and Informational Meeting, Effective Health Care Program, November 9, 2020. The prototypes are under development by the American Institutes for Research (AIR) and will be tested at health sites in January 2021.

26 Repository Steward Interview and Informational Meeting, Effective Health Care Program, October 22, 2020. Other sources of content include content from earlier EHC-supported projects. Id.

27 Repository Steward Interview and Informational Meeting, Effective Health Care Program, November 9, 2020. For purposes of this document, "formal API" refers to an API that has been documented and supported.

3.1.1.3 Data Schemas

Each product catalogued on the EHC website is assigned one or more values from the following categories:

- Audience (e.g., Consumers or Professionals)
- Product Type (e.g., Systematic Review or White Paper)
- Health Topic (e.g., Body Location/System—Brain and Nerves or Disorders and Conditions—Injuries and Wounds)
- Status (e.g., Draft or Archived)
- Methods (e.g., Original Methods Research: Systematic Reviews or Guidance on Methods for Registries)
- Authoring Institution (e.g., ECRI Institute or Tufts University—New England Medical Center)

Appendix E presents a crosswalk of these values with those in other repositories.

3.1.1.4 Application Programming Interfaces

End users can search the EHC Program's website through a proprietary search service that does not offer a formal documented API.[28] Information reported by EHC Program website stewards indicates that, while it would be possible to add an API, this would involve significant effort and, accordingly, is not a likely option in the near term. For CEDAR, this means engaging in other means to ingest information from the EHC Program.[29]

The CEDAR RI can instead invoke the EHC Program search function programmatically by creating and submitting requests mimicking the results of submitting the web search form that EHC supports. Search results would need to be "scraped" from the resulting web page(s). This form of integration is fragile because:

- If the EHC web search form changed, that change could impact the ability of CEDAR to invoke the search function.
- If the format of the returned search result page changed, that change could impact CEDAR's capability to extract the search results from the page.
- If the format of the returned search result page is not consistent across different results, then CEDAR will have to handle many special cases, adding complexity and uncertainty.

To assess the feasibility of this type of integration, the website search form and search result pages were evaluated in detail. The remainder of this subsection describes the findings of this investigation, and the following subsection provides an assessment of the integration using this approach.

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[28] Repository Steward Interview and Informational Meeting, Effective Health Care Program, October 22, 2020. DEXi is a proprietary machine-learning search service that scans all AHRQ content.

[29] Repository Steward Interview and Informational Meeting, Effective Health Care Program, October 22, 2020.

Inspection of the uniform resource locators (URLs) created by the EHC web search form reveals the following structure:

URL prefix: `https://effectivehealthcare.ahrq.gov/products?`

URL query parameters:

- `search_api_views_fulltext` – value is free text to search for in products. For example, `search_api_views_fulltext=atrial fibrillation` would search for products related to atrial fibrillation.
- `f[n]` – defines a filter attribute, where *n* is a monotonically increasing value starting at 0. For example, `f[0]=field_product_type:systematic_review` would restrict the list of matching products to systematic reviews.

Using the foregoing example of atrial fibrillation, the results web page contains one HTML list item for each matching result as follows:

```
<li class="ehc-item">
 <div class="item-content">
 <div class="item-header">
 <a href="/products/stroke-atrial-fibrillation/research">Stroke Prevention in
Atrial Fibrillation</a>
 </div>
 <div class="item-meta">
 <div class="item-type">
 <span class="field-content">Systematic Review</span>
 </div>
 <div class="item-type">
 <span class="field-content badge badge-default">Archived</span>
 </div>
 <div class="item-date">
 <span class="field-content">August 23, 2013</span>
 </div>
 </div>
 </div>
</li>
```

In lexical order, the metadata for each search result is:

1. A unique identifier for the product: "/products/stroke-atrial-fibrillation/research"
2. The title of the product: "Stroke Prevention in Atrial Fibrillation"
3. The type of the product: "Systematic Review"
4. The status of the product: "Archived"
5. The date of the product: "August 23, 2013"

Therefore, a search for atrial fibrillation returns all products (showing 30 products per page) with that phrase; the search can be filtered by criteria, including the product type, whether the product is currently active or timely, and when it was published on EHC.

Before CEDAR can determine other metadata values for an EHC Program product and return them to users of the CEDAR API, it would need to perform an exhaustive set of EHC Program queries using each of the available metadata filter values to build a local cache of which products match which metadata values. Given 400-plus metadata filter values (290 of which are health topics) and 1,139 products at the time of writing, this would generate a maximum of 400 x 1,139/30 = 15,186 queries (assuming every product matched every metadata value and a fixed 30 products per query results page). Based on in-browser performance, each query takes approximately 3.5 seconds, which sets an upper bound of approximately 15 hours to fully index the EHC Program website. If one assumes that each product will match only 10 percent of the metadata values, then the actual time to index would be 1.5 hours.

3.1.2 Integration Assessment

The lack of a formal web API makes robust integration of EHC into CEDAR feasible but challenging. CEDAR would need to mimic the web search form to perform searches and adopt a web page scraping approach to retrieve search results. In addition, to successfully return rich metadata with search results, CEDAR would need to periodically (perhaps weekly) build a local index of EHC content using an exhaustive set of searches to determine which products match each metadata value. The downside to this approach involves fragility and currency:

1. **Fragility**—changes to the EHC web search form or results page could break CEDAR integration in ways that would require intervention by the CEDAR developer to fix the break.
2. **Currency**—new products on the EHC would only be visible to CEDAR users following the next build of the local CEDAR index.

An alternate approach to integration would be for CEDAR to ingest some form of periodic database dump from the system that provides the EHC website search functionality. It would likely provide better performance by relying on a private CEDAR-EHC form of integration and requiring additional work by the team supporting the EHC website.

3.2 The Systematic Review Data Repository

The SRDR is a collaborative, web-based resource containing systematic review data that functions as both a data repository and a data extraction tool.[30] It is currently stewarded by the Brown University EPC.[31]

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[30] AHRQ, Evidence-based Practice Center (EPC) Program Overview, https://www.ahrq.gov/research/findings/evidence-based-reports/overview/index.html.

[31] SRDR, About the Systematic Review Data Repository, https://srdr.ahrq.gov/about. Evidence-based Practice Centers are academic and other research institutions contracted by the EHC Program to evaluate and summarize healthcare evidence. The current EPCs are Brown University, ECRI Institute-Penn Medicine, Johns Hopkins University, Kaiser Permanente Research Affiliates, Mayo Clinic, Minnesota Evidence-based Practice Center, Pacific Northwest Evidence-based Practice Center–Oregon Health and Science University, RTI International–University of North Carolina, and the University of Southern California. AHRQ, Evidence-based Practice Center (EPC) Program Overview, https://www.ahrq.gov/research/findings/evidence-based-reports/overview/index.html.

The SRDR is intended to improve access to data for users seeking to review evidence, promote transparency and reliability of the systematic review process, facilitate cooperation across related resources, and enhance efficiency of creating and updating systematic reviews.[32] The ultimate purpose is to influence and impact the development of clinical decision support artifacts.[33] The SRDR and its updated version, SRDR Plus (SRDR+),[34] use an API to provide information in the systematic review to other systems. A requirement of EPC contractors, who are some of the authors of systematic and evidence reviews, is to upload data files from evidence reviews into the SRDR. Approximately 60–70 percent of projects included in the SRDR are generated by an EPC.[35]

3.2.1 Technical Specifications

3.2.1.1 Architecture

The front (or user-facing) end of the SRDR website is developed with Ruby on Rails as the application framework.[36] While a small portion of client interactions use the React JavaScript library, CEDAR can ignore this due to the availability of a Rails-based API. Nginx is the front-end web server.[37] The application server is load balanced across multiple running instances to handle application load and provide failover support. Background tasks are managed with Active Job, which uses Sidekiq for queueing activities and Redis as the back-end data store.[38]

For the past 4 years, the Brown University EPC has hosted the SRDR on Amazon Web Services (AWS) servers. Typically, this is configured with two front-facing web servers spooled up from images on AWS to allow the service to ramp up on heavy load days.[39]

3.2.1.2 Data Sources

The bulk of the content in the SRDR is predominantly reviews and evidence related to health, although it does include reviews and evidence in other related subject matter areas, such as patient and healthcare worker education.[40]

Ingestion of data into the SRDR has evolved. Where previously EPCs could add a flat file to the system for end users to download,[41] evidence tables are now loaded into the SRDR in a structured way.[42] The reports that originate from data within the SRDR are posted on the

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32 SRDR, About the Systematic Review Data Repository, available at https://srdr.ahrq.gov/about.

33 Repository Steward Interview and Informational Meeting, Systematic Review Data Repository, October 22, 2020.

34 AHRQ, About the Systematic Review Data Repository Plus (SRDR+), https://srdrplus.ahrq.gov/about. SRDR+ and SRDR will run in parallel for a period of time to allow time for users to prepare to migrate to SRDR+. Id.

35 Id.

36 Id.

37 Id.

38 Id.

39 Id.

40 Id.

41 Repository Steward Interview and Informational Meeting, Effective Health Care Program, November 9, 2020.

42 New contractual requirements on EPC participants require the addition of data in a structured format. Repository Steward Interview and Informational Meeting, Systematic Review Data Repository, October 22, 2020.

Effective Health Care Program website. Notably, while SRDR links to the EHC Program website, there is no reciprocal link to provide content from the EHC Program back to the SRDR.[43] The lack of reciprocal links may make it more difficult for CEDAR to cross-index artifacts, impacting the ability to achieve the aspect of the FAIR principle of "interoperable" that "(meta)data include qualified references to other (meta)data."[44]

3.2.1.3 Data Schemas

The information in the SRDR is stored in a relational database (MariaDB®).[45] Every project is provided a permanent identifier (a Digital Object Identifier) that allows linking SRDR data to data on SRDR+.[46] The linkage is provided via URL.

The information in the SRDR is anchored around key research questions. The SRDR interface allows the user to build out data extraction forms. Users can structure data extraction freely.

3.2.1.4 Application Programming Interfaces

SRDR offers a RESTful[47] API that returns data in JSON (JavaScript Object Notation) format. The SRDR runs two versions of the API: one that is proprietary and a second that uses FHIR-structured JSON.[48] The API is well documented online.[49] Search facets focus on topics related to bucketed conditions (e.g., genetic conditions or heart and vascular disease) as well as methodology.[50]

3.2.2 Integration Assessment

The CEDAR RI can make use of the SRDR's formal, well-defined API to perform RESTful queries to retrieve data from the repository. The SRDR did not initially provide an API entry point for retrieving all publicly accessible data. The SRDR team has subsequently accepted an open source code contribution to SRDR+ that adds such an entry point.[51] This new functionality allows CEDAR to query it periodically to retrieve the most recent data.

3.3 National Guideline Clearinghouse

The National Guideline Clearinghouse was a database-driven, web-based resource targeted to healthcare professionals, health plans, integrated delivery systems, and other users seeking open access to objective, detailed information on evidence-based clinical practice guidelines. Public access to the original NGC site was removed in 2018 when Federal funding was withdrawn. The

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43 Repository Steward Interview and Informational Meeting, Effective Health Care Program, November 9, 2020.

44 FAIR Principles, available at https://www.go-fair.org/fair-principles/i3-metadata-include-qualified-references-metadata/.

45 Repository Steward Interview and Informational Meeting, Systematic Review Data Repository, October 22, 2020.

46 Id.

47 "REST" is an acronym for Representational State Transfer and is a software architectural style commonly used to create interactive web applications.

48 Id.

49 https://srdrplus.ahrq.gov/apipie.

50 AHRQ, SRDR Advanced Search, available at https://srdr.ahrq.gov/adv_search, and AHRQ, Search EPC Reports, available at https://www.ahrq.gov/research/findings/evidence-based-reports/search.html.

51 https://github.com/jensjap/srdrPLUS/pull/243.

clearinghouse remains offline but is included in this scan because repository content is intended to be indexed with the CEDAR RI.[52]

3.3.1 Technical Specifications

3.3.1.1 Architecture

The NGC program published products via a website built using a proprietary CMS.[53] NGC categorized products using a common set of metadata that allowed the CMS to manage heterogenous source material in a homogenous way. NGC used the Unified Medical Language System (UMLS) taxonomy and relied on Medical Subject Headings (MeSH)[54] and SNOMED-CT[55] as the main vocabularies to tag content and concepts of content, and in the case of MeSH, to drive searches on the website.[56] Links between content in NGC and EPC systematic reviews, which allowed visibility into where research investments were used in guidelines, were included in NGC web pages.[57]

3.3.1.2 Data Sources

The primary data sources for the content within the NGC were guidelines created by medical professional societies, other government agencies, health plans, and other types of guideline developers. Guideline developers' intellectual property was protected by obtaining permissions and ensuring content was copied verbatim from guidelines. With appropriate permissions as defined by copyright, guidelines were able to be downloaded by end users.[58]

3.3.1.3 Data Schemas

Although the structure of NGC's Silverchair CMS is proprietary, the metadata used to categorize NGC content is public. Each guideline published on NGC was assigned one or more values from the following categories:[59]

- Age of Target Population (e.g., Adolescent [13 to 18 years])
- Clinical Specialty (e.g., Cardiology)
- Guideline Category (e.g., Rehabilitation)
- Implementation Tools (e.g., Treatment)

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52 AHRQ, About NGC and NQMC, https://www.ahrq.gov/gam/about/index.html.

53 The CMS that the NGC used was developed by Silverchair. Repository Steward Interview and Informational Meeting, National Guideline Clearinghouse, October 28, 2020.

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

55 SNOMED International, Use SNOMED CT, https://www.snomed.org/snomed-ct/Use-SNOMED-CT.

56 Repository Steward Interview and Informational Meeting, National Guideline Clearinghouse, October 28, 2020. Meeting participants also noted that, while not needed, RxNORM and LOINC were also vocabularies that could be supported by NGC.

57 Id.

58 Id.

59 Internet Archive Wayback Machine, AHRQ National Guideline Clearinghouse, http://web.archive.org/web/20160101002421/http://guideline.gov/.

- Intended Users (e.g., Physical Therapists)
- Institute of Medicine Care Need (e.g., Getting Better)
- Institute of Medicine Domain (e.g., Effectiveness)
- Methods Used to Analyze the Evidence (e.g., Review of Published Meta-Analyses)
- Methods Used to Assess the Quality and Strength of the Evidence (e.g., Expert Consensus [Delphi Method])
- Methods Used to Formulate the Recommendations (e.g., Expert Consensus [Consensus Development Conference])
- Guidelines Inclusions (e.g., Quick Reference Guides/Physician Guides)
- Organization Type (e.g., Independent Expert Panel)
- Organizations (e.g., American College of Cardiology Foundation)
- Publication Year
- Gender of Target Population

Appendix E presents a crosswalk of these values with those in other repositories.

3.3.1.4 APIs

The NGC website had been searchable by end users through a search service that lacked a formal API.[60] The NGC website included instructions for web developers to embed NGC search forms in their own websites.[61] Although there is no formal API, if NGC is re-released, CEDAR could invoke the NGC search function programmatically by creating and submitting requests that mimicked the results of submitting the web search form that NGC supports. Search results would need to be scraped from the resulting web page(s). This form of integration would be fragile because (1) if the NGC web search form changed, that change could diminish CEDAR's capability to invoke the search function, and (2) if the format of the returned search result page changed, that change could reduce CEDAR's capability to extract the search results from the page.

Analysis of the URLs created by the NGC web search form reveals the following structure:

URL prefix: `http://www.guideline.gov/search/results.aspx?`

URL query parameters:

- `type` – value is fixed to "external", i.e., `type=external`
- `term` – free text to search for products containing specific words or terms. For example, `term=atrial fibrillation` would search for products related to atrial fibrillation.

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60 This search service would have been part of the Silverchair CMS.

61 Internet Archive Wayback Machine, NGC Web Developer Information, http://web.archive.org/web/20160104234326/http://www.guideline.gov/for-web-developers/create-search.aspx.

- `field_code` – defines a filter category, using a code. For example, `106=453` restricts the list of matching products by ages of target population (code `106`) to those applicable to adults (19 to 44 years) (code `453`).

If NGC can be re-released in the future, it would benefit from offering a formal web API.[62] Such an API could support programmatic searching guidelines. With such an API, integration with CEDAR would be relatively straightforward, although it would still require metadata mapping, translation, and normalization (which itself could also be relatively simple, depending on the source of the metadata).

3.3.2 Integration Assessment

The lack of a formal web API would make robust integration of NGC into CEDAR challenging. If NGC is re-released with its current technical specifications, CEDAR would need to mimic the web search form to perform searches and adopt a web page scraping approach to retrieve search results. If the search results did not include full metadata for each product, any CEDAR attempt to return rich metadata with search results would require periodically building a local index of NGC content using an exhaustive set of searches to determine which products matched each metadata value. Here again, there would be two downsides to this approach:

1. **Fragility**—if changes to the NGC web search form or results page are made, this could break CEDAR integration in ways that would require intervention by the CEDAR developer to fix.
2. **Currency**—if new products were introduced into the NGC, such new products would only be visible to CEDAR users following the next build of the local CEDAR index.

Inclusion of a formal web API in any re-release of NGC would address both challenges. Note, however, that API-based integration still has costs: non-standard/custom APIs require dedicated software in CEDAR to query the API; metadata needs to be translated or normalized before inclusion in the CEDAR index.

3.4 U.S. Preventive Services Task Force Recommendations

The U.S. Preventive Services Task Force is "an independent, volunteer panel of experts in prevention and evidence-based medicine."[63] The goal of the USPSTF is to improve the health of all Americans by developing evidence-based recommendations about clinical preventive services such as screenings, counseling services, and preventive medications.[64] Recommendations are primarily targeted to people without signs or symptoms of disease or medical conditions.

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62 Repository Steward Interview and Informational Meeting, National Guideline Clearinghouse, October 28, 2020.

63 U.S. Preventive Services Task Force, About the USPSTF, https://www.uspreventiveservicestaskforce.org/uspstf/about-uspstf.

64 Id.

3.4.1 Technical Specifications

3.4.1.1 Architecture

The USPSTF provides access to its information using a web browser, a mobile application, an embeddable widget, and a RESTful API. All data queries from the web browser, mobile application, and embeddable widget are routed through its RESTful API.[65] The API is developed using the Rust programming language.[66]

3.4.1.2 Data Sources

The USPSTF creates recommendations by working with researchers from Evidence-based Practice Centers to develop a research plan, conduct literature searches of existing peer-reviewed evidence (using MEDLINE®, the Cochrane Central Register of Controlled Trials, and other databases), and draft an evidence review summarizing the evidence on a topic of interest.[67] Public comments are accepted on draft evidence reviews and recommendations before final evidence reviews and recommendation statements are issued. Only final, published recommendations are exposed by the USPSTF API. Approximately 136 specific recommendations have been published at the time of this review.[68] Each year, the USPSTF adds or updates between approximately 12 and 15 recommendations.[69]

3.4.1.3 Data Schemas

Data returned by the USPSTF API include the following sections:[70]

- **Specific Recommendations.** These are recommendations aimed at a target population. Each specific recommendation links to one general recommendation and is assigned one grade. A specific recommendation may include multiple tools or supporting documents.
- **Grades.** Five letter grades (A, B, C, D, and I) represent the magnitude of the anticipated net benefit and the level of certainty associated with the recommendation.[71] The USPSTF describes each grade as follows:
    - **A –** The USPSTF recommends the service. There is high certainty that the net benefit is substantial.
    - **B –** The USPSTF recommends the service. There is high certainty that the net benefit is moderate or there is moderate certainty that the net benefit is moderate to substantial.

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65 https://www.uspreventiveservicestaskforce.org/apps/.

66 Repository Steward Interview and Informational Meeting, USPSTF, October 27, 2020.

67 https://www.uspreventiveservicestaskforce.org/uspstf/procedure-manual/procedure-manual-section-4-evidence-review-development.

68 U.S. Preventive Services Task Force. Prevention Task Force Web application. https://www.uspreventiveservicestaskforce.org/webview/#!/.

69 Id.

70 AHRQ, Prevention TaskForce API, Instructions for Use, https://www.uspreventiveservicestaskforce.org/files/preventiontaskforce_data_api_wi.pdf.

71 https://www.uspreventiveservicestaskforce.org/apps/gradedef.jsp.

- **C –** The USPSTF recommends selectively offering or providing this service to individual patients based on professional judgment and patient preferences. There is at least moderate certainty that the net benefit is small.
- **D –** The USPSTF recommends against the service. There is moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits.
- **I –** The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of the service. Evidence is lacking, of poor quality, or conflicting, and the balance of benefits and harms cannot be determined.

- **General Recommendations.** These are recommendations for a general population. A single general recommendation may be categorized using multiple categories (though of note, some of these categories can also apply to specific recommendations). General recommendations have four distinct subsections:
  - Rationale
  - Clinical reasoning
  - Recommendations from other organizations
  - Discussion
- **Tools.** External documents included with a recommendation that contain supporting information. The tools section contains a list of external reference with URLs.
- **Categories.** The USPSTF contains 12 clinical categories. Each general recommendation included in the USPSTF repository is assigned to at least one clinical category.

3.4.1.4 APIs

The USPSTF API supports seven input (search) parameters:[72]

- `age` – integer
- `sex` – Male, Female
- `pregnant` – Y, N (requires sex of Female)
- `tobacco` – Y, N
- `sexuallyActive` – Y, N
- `grade` – A, B, C, D, I (multiple values)
- `tools` – Y, N (returns only tools if Y)

A USPSTF query string might look like:

```
?age=36&sex=Female&pregnant=Y&tobacco=N&sexuallyActive=N&grade=A&grade=B&grade=C&grade=D&grade=I&tools=N
```

Search results are returned in JSON format in the foregoing data schema.

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[72] AHRQ, Prevention TaskForce API Instruction for Use, https://www.uspreventiveservicestaskforce.org/files/preventiontaskforce_data_api_wi.pdf.

The USPSTF provides an access token for each registered user. The USPSTF uses access tokens to track user activities. Beginning March 2021, an access key will be required to access the USPSTF API.[73]

3.4.2 Integration Assessment

USPSTF provides data through its Prevention Task Force API using a JSON data format. CEDAR RI would use standard RESTful queries to access JSON data and build a local index based on the data schema described. USPSTF does not have a regular release schedule or a clearly identified version number.[74] The CEDAR API would need to periodically query the USPSTF API to obtain the most updated data.

3.5 CDS Connect

CDS Connect provides Clinical Decision Support artifacts that are based on clinical practice guidelines, peer-reviewed articles, best practices, and other content identified via PCOR.[75] Through the AHRQ CDS Connect Project, the Health FFRDC has been leading the development processes for CDS Connect, including the clinical and technical translation of guidelines into computable CDS, testing and monitoring, implementation protocols, and feedback loops.

Central to CDS sharing is the CDS Connect Repository of CDS knowledge artifacts.[76] Through this repository, access is available to CDS artifacts generated from CDS research and clinical guidelines, which offer advanced technical resources and tools to aid in the implementation of the CDS logic. The CDS Connect Repository offers structured data, aggregated resources, and the ability to access open-source offerings that supporting offering, testing, and executing in the international standard Clinical Quality Language (CQL).[77]

3.5.1 Technical Specifications

CDS Connect uses two primary systems functions: the front end and back end, which store and provide authorized users with access to CDS artifacts. Users access CDS Connect through the front end to search, upload and download, view, and browse CDS artifacts. The back end addresses front-end user requests by indexing and searching the underlying CDS Connect repository.

3.5.1.1 Architecture

The CDS Connect repository has four basic layers: data, transfer, application, and presentation.[78]

- **Data Layer.** This layer provides persistent storage for CDS Connect repository artifacts and related data and metadata. Storage is provided by the MySQL 5.6 relational database.

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73 Repository Steward Interview and Informational Meeting, USPSTF, October 27, 2020.

74 Id.

75 AHRQ, Patient-Centered Outcomes Research, Clinical Decision Support, Welcome to CDS Connect, https://cds.ahrq.gov/cdsconnect.

76 Explore CDS Connect Artifacts, https://cds.ahrq.gov/cdsconnect/artifact_discovery.

77 AHRQ, About CDS Connect, https://cds.ahrq.gov/cdsconnect/about.

78 https://cds.ahrq.gov/collaboration/display/CCD/System+Architecture.

- **Transfer Layer.** This layer provides support for communicating data to the end user. Data transfer is web based and takes place using secure Hypertext Transfer Protocol (HTTPS), implemented using the Apache web server.
- **Application Layer.** This layer provides the business logic for the repository and is implemented using the Drupal 8 content management framework.
- **Presentation Layer.** This layer displays repository data to the end user. It uses common web technologies for presenting data such as Hypertext Markup Language (HTML), Cascading Style Sheets (CSS), and JavaScript.

CDS Connect is hosted on AWS servers.

3.5.1.2 Data Sources

The CDS Connect Repository contains CDS artifacts. The CDS artifacts were initially seeded by CDS Connect team members, with expansion to authorized external users who can also enter artifacts directly into the CDS Connect repository, with official publication subject to Health FFRDC review and approval.[79]

3.5.1.3 Data Schemas

The CDS Connect Data Dictionary defines content types, forms, and taxonomies that make up CDS artifacts. When contributing to or updating artifacts in the repository, users enter data into a web form that accepts data as defined in the CDS Connect Data Dictionary. This information is managed and stored as Drupal nodes and then stored in a MySQL database.[80] The Data Dictionary contains the following:

- **Artifact Metadata.** The Artifact content type defines the metadata fields associated with CDS artifacts. The metadata fields include, but are not limited to, Name, Identifier, Version, Status, Artifact Type, Keywords, Creation Date, Publisher, Contributor, MeSH Topics, Knowledge Level, Related Artifacts, Triggers, Cautions, Approval Date, Expiration Date, Last Review Date, Publication Date, Source, References, Recommendation Statement, and Strength of Recommendation.
- **Organization.** The Organization content type contains details about external organizations that may be referenced as stewards, contributors, or publishers of artifacts. Fields include Name, Organization Type, and Logos.
- **Source.** The Source content type contains details about the source, guidelines, rules, guidance, or other original material used to develop CDS artifacts. Fields include Name, Identifier, Description, Source Type, Clinical Domain, and Authors.
- **Artifact Type Taxonomy.** The Artifact Type taxonomy describes possible values representing an artifact's type, such as Alert, Calculator, and Data Summary.

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[79] AHRQ, CDS Connect FAQs, https://cds.ahrq.gov/cdsconnect/faq. To contribute to the repository, an external party works with the CDS Connect team to obtain author credentials and to discuss the data and the format expected to be contributed, as well as by working through review and feedback of the proposed contribution.

[80] AHRQ, CDS Connect System Document, https://cds.ahrq.gov/collaboration/display/CCD/CDS+Connect+System+Document.

- **Clinical Domain Taxonomy.** The Clinical Domain taxonomy describes possible values representing an artifact's clinical domain. The current values were derived from the American Board of Medical Specialties' Guide to Medical Specialties[81] and evolved based on CDS Connect stakeholder work group feedback.
- **Knowledge Level Taxonomy.** The Knowledge Level taxonomy describes possible values representing CDS knowledge levels.
- **License Taxonomy.** The License taxonomy describes possible values representing an artifact's license.
- **Medical Subject Headings Taxonomy.** The MeSH taxonomy is based on the corresponding vocabulary available from the U.S. National Library of Medicine.[82]
- **Organization Type Taxonomy.** The Organization Type taxonomy describes possible values representing types of organizations.
- **Source Type Taxonomy.** The Source Type taxonomy describes possible values representing types of documents from which CDS may be derived.
- **Status Taxonomy.** The Status taxonomy describes possible values representing an artifact's status. Defined values include Draft and Active.

3.5.1.4 APIs

CDS Connect currently has two implemented APIs: the CDS Connect API and the Authoring Tool API (for the front-end web application only), with the FHIR Clinical Reasoning API expected to be implemented in the future.[83] The key API for CEDAR RI purposes is the CDS Connect API. This API allows users to retrieve or create CDS artifacts using a native CDS Connect format. The API implementation is available on GitHub[84] and maps CDS artifacts between the CDS Connect data model and the API's JSON schema. The API was designed to comply with the OpenAPI standard,[85] in which documentation on the artifact schema is provided via an advertised GET endpoint and returned to the requester as JSON.

3.5.2 Integration Assessment

CDS Connect's APIs allow users to download data provided by artifact authors as CQL/Expression Logical Model (ELM) files, FHIR Clinical Reasoning resources, and CDS Connect native artifacts. All three APIs return JSON data format in response. The CEDAR RI

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81 American Board of Medical Specialties, ABMS Guide to Medical Specialties (2020), https://www.abms.org/wp-content/uploads/2020/11/ABMS-Guide-to-Medical-Specialties-2020.pdf.

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

83 AHRQ, CDS Connect System Document, https://cds.ahrq.gov/collaboration/display/CCD/CDS+Connect+System+Document. The Authoring Tool API allows authorized users to update artifact metadata using JSON representation of CQL and ELM logic files. The FHIR Clinical Reasoning API allows users to update artifact metadata using JSON representation of FHIR Clinical Reasoning objects (https://meshb.nlm.nih.gov/treeView). Current supported fields are resourceType, status, type, contributor, purpose, usage, relatedArtifact, and publisher.

84 https://github.com/AHRQ-CDS/AHRQ-CDS-Connect-API.

85 https://swagger.io/specification/.

can use standard RESTful queries to access all published CDS Connect resources through the CDS Connect API. The FHIR Clinical Reasoning API may also provide additional data via a FHIR interface.

CDS Connect provides a version number as part of its artifact metadata, but it does not have a regular release schedule.[86] The CEDAR API will need to periodically query the CDS Connect API and use the artifact's version number to identify new and updated artifacts.

4 Identified Risks

4.1 Technical Risks

This section captures any differences or variances between the technical specifications of the AHRQ PCOR resources that may impact the development of the CEDAR Reference Implementation. Generally, integration with the CEDAR RI will be simplified when a repository offers an API and uses a common metadata format; without an API, there is a risk in that integration is more fragile.

4.1.1 Limitations on Data Access

The CEPI repositories differ in the availability of data. The existence of licenses and other contractual requirements for access does not necessarily indicate a lack of FAIRness if metadata conveys the requirements for access. But when these requirements are burdensome or delay access to the artifact, as is the risk when repositories lose funding, FAIRness decreases. For CEDAR, the existence of intellectual property and other limitations on data access should not be a gap that affects integrating information from the repositories, but it could potentially impact how the end user might consume the data or the data's availability.

4.1.2 Non-Standard Interfaces

Several of the CEPI repositories lack a documented API to provide access to the catalog of products they hold and the metadata about those products. This limits the efficiency and stability of CEDAR integration as follows:

- **Efficiency.** Each repository requires custom CEDAR software to index the repository contents. Some repositories may require many interactions to capture all metadata facets of each product.
- **Stability.** Small changes to the repository website that would not impact human usage could easily break CEDAR algorithms for indexing those repositories. For example, changing the name of an HTML element class that CEDAR uses to identify a particular piece of metadata on an HTML web page would not be visible to a human reader of the page but would prevent CEDAR from locating the correct metadata.

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[86] Depending on the status of the artifact contributed to the repository as indicated in its metadata (e.g., draft, active, or retired) and certain other criteria, CDS Connect sets out expectations for its contributors' review and updates. A table to guide review and update expectations can be found at https://cds.ahrq.gov/cdsconnect/faq.

Similarly, one repository is currently offline and unavailable to the public. Lack of certainty about the future of offline repositories leaves a gap that can also impact CEDAR development.

4.1.3 Maturity of Standards

Some of the FHIR implementation guides and resources relevant to the RI are at a low maturity level. These guides and resources have not been tested extensively and may change when implementer community feedback is incorporated.

For example, the CEDAR RI will use the FHIR Citation resource to manage data about an artifact citation and metadata about the cited resource/product. The FHIR Citation resource is considered to be at a low maturity level because it is new to the FHIR specification and is changing rapidly as the implementer community provides input and tests its use in connectathons. The RI will need to track developments in the specification and adapt to the changes as they occur.

4.1.4 Content Diversity

4.1.4.1 Identification of Content Type

Each CEPI repository contains various artifacts (sometimes referred to as products), including white papers, evidence reviews and reports, and guidelines. These artifacts are not identified consistently across all CEPI repositories. This means that the CEDAR RI may have to adapt or find a flexible way to identify these differently identified artifacts when developing its search function.

4.1.4.2 Differences in Technical Implementation

The CEPI repositories are not technically consistent with each other and implement different system designs. This diversity of technical implementations will impact the CEDAR RI as it interacts with each of these distinct systems. Noted differences include whether an API is offered and differences in the handling of metadata:

- Not all repositories include an API. Repositories that do provide APIs do not follow a common standard. This impacts interoperability and reusability because repository-specific customization is required to access repository data by the CEDAR RI or any other system where repository data access is desired.
- The repositories do not consistently define metadata. Lack of a shared metadata model is a technical challenge requiring the CEDAR RI to implement a separate indexer for each repository and map between the native repository metadata model and the model defined within CEDAR.

4.2 Other Risks

The main purpose of this environmental scan was to evaluate the technical specifications of the AHRQ CEPI PCOR repositories and factors that could impact technical integration of the repositories with the CEDAR RI. Other related factors relevant to CEDAR RI development (FAIR, health IT standards, other repositories, and stakeholders), however, also raise considerations and potential challenges.

4.2.1 Tools to Assess FAIR Data Principles

A key goal of the CEDAR RI is to make the AHRQ CEPI repositories more FAIR. The FAIR Data Principles are purposefully non-prescriptive to ensure fluid interpretation and application to different domains. This lack of definition, however, means that many of the existing tools that are currently available to assess FAIRness of data or data repositories are not specific to healthcare or, more specifically, to patient-centered outcomes research. This lack of application to CEPI repositories specifically presents a risk to adequate assessment of FAIRness.

4.2.2 Non-Uniform Metadata

The AHRQ CEPI repositories do not manage or make content available to users in ways that are consistent across the repositories. Variations in available metadata across the repositories can impact findability of information. This challenge has been observed in other initiatives, such as the NIH Data Commons, which has strategized ways to harmonize data and metadata through a "Crosscut Metadata Model."[87]

4.2.3 Non-Uniform Access Mechanisms

Lack of APIs in repositories impacts accessibility and interoperability, and lack of a common exchange format, such as FHIR, impacts the FAIR facets of interoperability and reusability.

4.2.4 Stakeholder Engagement

Stakeholder engagement necessary to inform the CEDAR RI development may be initially impacted by the ongoing COVID-19 pandemic and will require, at least initially, only virtual engagement with stakeholders. The lack of in-person engagement risks limiting stakeholder access and input critical to effective RI development.

5 Conclusion and Recommendations

Several key findings emerged in the environmental scan that can drive the progress of the CEDAR RI.

The technical review indicated variety in technical specification, content and content identification, and API usage across the CEPI repositories, which in some cases may complicate, but which will ultimately not be a bar to, integration. Current methods for integration with the CEDAR RI will likely need to be revisited as development progresses, depending upon changes to technical aspects of the CEPI repositories, including any changes or updates to the repository websites and as decisions are made regarding the future of NGC. For CEDAR, the existence of intellectual property and other limitations on data access should not be a gap that affects integrating information from the repositories, but it could potentially impact the ease with which

[87] Data Commons Pilot Phase Consortium, Progress in 180 Days, https://public.nihdatacommons.us/Progress180_4YP/ (discussion of web interfaces that can access arbitrarily complex datasets; the need for uniquely identifiable research objects, persistent identifiers, and harmonization of data models; creation of a crosscut metadata model to render diverse metadata into a common exchange format; and a software platform to perform FAIR assessments [FAIRshake]).

the end user might consume the data or the data's availability, which can impact the FAIRness of the evidence.

Review of other repositories revealed a significant number of associations that offer guidelines—some of which already provide links to or reference AHRQ materials and CEPI repositories—and other repositories (Federal repositories and some generalist repositories) that offer extensive data, methods for consistent data ingestion, and the technical capacity to potentially integrate more easily with a tool like CEDAR. Other domain-specific repositories exist that offer datasets of potential interest in the PCOR domain, but typically with restricted access.

The CEDAR RI can benefit from changes to the CEPI repositories, such as standardization of artifact structure and vocabularies, that would facilitate improved indexing of existing and new content as well as linkage between repositories. For example, standardized keyword vocabularies would support identification of commonalities across different repositories. Establishing recommendations for data stewardship, especially those aligned with FAIR Data Principles, can also facilitate future expansion of CEDAR to include other repositories should that be deemed desirable.

Based on these findings and the review of risks, the following near- and long-term recommendations are offered:

Near-Term Recommendations

- **Recommendation 1:** Develop FAIR assessment criteria aligned to the patient-centered outcomes research domain to assess the AHRQ CEPI repositories. Assessment criteria could be made available to other repositories interested in aligning with CEDAR so those repositories can self-assess FAIRness.
- **Recommendation 2:** 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 in order to enhance the CEDAR RI.
- **Recommendation 3:** Investigate if there are any technological barriers for clinicians serving specific populations that would impact ease of use of the CEDAR RI.
- **Recommendation 4:** 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.

Long-Term Recommendations

- **Recommendation 5:** Future repositories and/or versions of AHRQ CEPI repositories should be contractually required to include RESTful API(s), considering FHIR or other standards as appropriate, to enable smooth connection and interoperation with CEDAR. In the alternative, AHRQ could require repositories to follow a very specific, CEDAR-recommended API standard.

  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.

  Recommendation 6: 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.

- **Recommendation 7:** 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.

Near- and Long-Term Recommendations

- **Recommendation 8:** 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.
- **Recommendation 9:** 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,[88] 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.
- **Recommendation 10:** To align with FAIR Data Principles, AHRQ CEPI repositories should include permanent identifiers in any offered APIs that will allow CEDAR to maintain an enduring link to the source CEPI repository.
- **Recommendation 11:** 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.

[88] Final Rule, 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program, 85 FR 47099 (August 4, 2020), and Final Rule, Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Interoperability and Patient Access, 85 FR 25510 (May 1, 2020).

Appendix A FAIR White Paper and Tool Assessments

A.1 FAIR Introduction

In 2016, the FORCE 11 community published the initial set of FAIR Data Principles—a set of community-defined principles and practices for scientific data stewardship that "allow both machines and humans to find, access, interoperate and re-use research data"[89] to make data Findable, Accessible, Interoperable, and Reusable. These principles are intended to apply to three cases: data, metadata, and infrastructure. The goal of the FAIR Data Principles is to continue to improve FAIRness across these cases. These original principles are expressed in the following list:[90]

Findable:

F1. (meta)data are assigned a globally unique and eternally persistent identifier.

F2. data are described with rich metadata.

F3. (meta)data are registered or indexed in a searchable resource.

F4. metadata specify the data identifier.

Accessible:

A1. (meta)data are retrievable by their identifier using a standardized communications protocol.

A1.1. the protocol is open, free, and universally implementable.

A1.2. the protocol allows for an authentication and authorization procedure, where necessary.

A2. metadata are accessible, even when the data are no longer available.

Interoperable:

I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.

I2. (meta)data use vocabularies that follow FAIR principles.

I3. (meta)data include qualified references to other (meta)data.

Re-Usable:

R1. meta(data) have a plurality of accurate and relevant attributes.

R1.1. (meta)data are released with a clear and accessible data usage license.

R1.2. (meta)data are associated with their provenance.

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89 https://www.force11.org/group/fairgroup/fairprinciples.

90 In the original guidelines, "(meta)data" is intended to indicate that "the principle is true for Metadata as well as for the actual, collected Data Elements in the Data Object (an identifiable Data item with Data elements + Metadata + an Identifier), but that the principle in question can be independently implemented for each of them." FORCE11, Guiding Principles for Findable, Accessible, Interoperable, and Re-usable Data Publishing, version b1.0, https://www.force11.org/fairprinciples.

R1.3. (meta)data meet domain-relevant community standards

A.2 Evaluation of Existing FAIR Assessment Tools

The original FAIR Data Principles were intentionally drafted in a non-prescriptive way. Following their publication, the original principles have been interpreted and applied to different assessment tools in varying ways. The Research Data Alliance (RDA) FAIR Data Maturity Model Working Group reviewed 12 such assessment tools and their respective maturity levels in efforts to develop a FAIR data maturity model.[91] The RDA noted that the "exact way to evaluate data" is best left to stakeholders to determine in consideration of community-specific needs and requirements.[92]

The RDA's work provided a foundation for evaluating those FAIR assessment tools and criteria that would align with the data and data maturity needs of the patient-centered outcomes research (PCOR) domain. Importantly, the RDA assessment did not contain any tools applicable to PCOR specifically. Tailored criteria supporting the PCOR domain, and Center for Evidence and Practice Improvement (CEPI) Evidence Discovery And Retrieval (CEDAR) specifically, will therefore be required to adequately measure the FAIRness of the Agency for Healthcare Research and Quality (AHRQ) CEPI repositories.

The following FAIR Evaluator Tools were analyzed by RDA and assessed by the MITRE team for applicability to CEDAR:

- DANS FAIRdat
- DANS FAIR Enough?
- FAIR Evaluator
- ANDS-NECTAR-RDS Fair Data Assessment tool
- WMO-Wide Stewardship Maturity for Climate Data
- CSIRO 5-Star Data Rating Tool
- Stewardship Maturity Matrix
- FAIR Metrics
- Data Stewardship Wizard
- Checklist for Evaluation of Dataset Fitness for Use
- RDA-SHARC Evaluation
- Data Use and Services Maturity Matrix

Each of the above-named tools was assessed except for the CSIRO 5-Star Data Rating Tool, which required login credentials.

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91 RDA, Results of an Analysis of Existing FAIR Assessment, https://www.rd-alliance.org/group/fair-data-maturity-model-wg/outcomes/results-analysis-existing-fair-assessment-tools.

92 RDA FAIR Data Maturity Model Working Group, Workshop #5 (October 23, 2019), presentation deck https://www.rd-alliance.org/system/files/documents/20191023_FAIR_WG_slides_v0.08.pdf.

A.3 Description of Criteria for Evaluation of Tools

Using the RDA assessment as a guide, the 12 FAIR assessment tools were assessed for applicability to the PCOR domain and the CEDAR RI using the criteria in Table A-1.

Table A-1. Anticipated Tool Assessment Criteria and Rationale for Inclusion

Assessment Criteria	Rationale
Description of Tool	Provides background information about the purpose and functionality of the tool.
Date Tool Created	Provides context about the age of the tool and frequency of updates.
Adherence to Original FAIR Principles	Assesses whether an assessment tool hews close to the original FAIR principles or interprets them broadly according to domain needs.
Intent/Goal of the Assessment Tool	Describes the purpose and intended usage of the tool to provide insights about the type of object assessed for FAIRness.
Tool Limitations and Implications of Limitations	Identifies any limitations that would impact the use of the tool for assessment of the CEPI repositories or artifacts within the PCOR domain.
Unique or Distinct Criteria	Identifies unique criteria and raises awareness of criteria that are prototypes versus well tested.
Domain Specific?	Identifies any specific domain for which the tool was created.
Intended Users	Intended user can provide insights into the type of assessment criteria included, as well as determine relevance of criteria for CEDAR and PCOR.
Common Criteria across Tools	Similar measures demonstrate broader applications beyond specific domains for which they have been applied.
Impact (on CEDAR)	Identifies tools that will align with CEDAR's scope and technical dependencies to ensure a more accurate assessment. For example, evaluating the FAIRness of an individual resource will provide a different result than the evaluation of the entire repository.

Tables A-2 to A-4 describe the results of the evaluation using the criteria described in Table A-1. Assessment revealed that these tools are not individually sufficient for the adequate evaluation of PCOR repositories because they are not PCOR domain specific. Individual aspects from several tools, however, can be incorporated into the development of a PCOR FAIR assessment.

Table A-2: Assessed Tools; General Information

Assessment Tool Name	Description of Tool	Intended User/Domain	Intent/Goal
DANS FAIRdat	Prototype FAIR data assessment tool evaluates the quality of a dataset via a questionnaire.	Not specified/no specific domain	Score the FAIRness of a dataset via a questionnaire and generate ratings of overall FAIRness and per facet of FAIR.

Assessment Tool Name	Description of Tool	Intended User/Domain	Intent/Goal
DANS FAIR Enough?	Checklist for data stewards contributing to digital repositories. Checklist assists in evaluating quality/FAIRness of the data as well as the trustworthiness of the selected data repository.	Data repositories seeking CoreTrustSeal compliance/CoreTrustSeal-compliant repositories	Assist data depositors in assuring information provided is "sufficient and in line with the principles of FAIR."
FAIR Evaluator	An application developed using Ruby on Rails. Enables machine testing of FAIRness and community contribution of new metrics.	Data stewards and publishers/no specific domain	Test FAIRness of data with a machine-readable process.
ANDS-NECTAR RDS FAIR Data Assessment Tool	Assesses the FAIRness of a dataset and, where applicable, how to enhance the FAIRness of a dataset.	Data librarians, technical staff, and software engineers/general science	Educational and informational self-assessment of FAIRness and starting discussion about how to make data more FAIR.
WMO-Wide Stewardship Maturity for Climate Data	This World Meteorological Organization tool enables dataset owners to assess and rate their datasets quantifiably based on internationally validated data stewardship best practices.	Climate data stewards/climate data	Assess data access, usability and usage, quality management, and data management on a maturity scale of levels one to five.
CSIRO 5-Star Data Rating Tool	Within CSIRO, the OzNome initiative works to connect Australian information infrastructures by developing a set of criteria under 14 sections. This tool assesses data collection, publication, and service provisioning.	CSIRO members/earth and environmental data (Australia)	Country- and organization-specific connection and management of data.
Stewardship Maturity Matrix	A stewardship maturity assessment model for digital environmental datasets. Adapts naming conventions of other maturity models and a progressive 5-point scale structure to evaluate nine components on scientific data stewardship.	NOAA users, stakeholders, and decision makers, and the environmental science community/environmental and geospatial data (NOAA)	Ensure and improve data quality, accessibility, usability, and production sustainability to enhance digital environmental data stewardship.
FAIR Metrics Questionnaire	A first version of a core set of FAIRness indicators that can be objectively measured with a semi-automated process and is applicable to all digital resources.	Content creators/no specific domain	Recommend objective measurement of FAIRness of digital resources and provide a template for different domains to derive community-specific FAIRness metrics.

Assessment Tool Name	Description of Tool	Intended User/Domain	Intent/Goal
Data Stewardship Wizard	A tool created by the European Life-Science Infrastructure (ELIXIR) (Czech Republic and Netherlands branches).	Researchers, data stewards, and data experts/life sciences and general science	Connect data stewards and researchers to efficiently compose data management plans for research projects.[93]
Checklist for Evaluation of Dataset Fitness for Use	Criteria[94] assessing research dataset fitness for use against CoreTrustSeal (CTS) repository requirements and FAIR principles. Evaluates a dataset for fitness for use in the CTS Repository Certification process.[95]	Data repository managers/CoreTrustSeal-certified repositories	Adoption as a supplemental part of the CoreTrustSeal repository certification process.
RDA-SHARC Evaluation	Fosters data sharing and helps researchers and scientists (non-domain specific) measure their level of consideration of the FAIR principles in their data management.	Researchers and scientists/no specific domain	Self-assessment tool for scientists to identify whether their activities are compliant with FAIR principles and quality of the data-sharing practices over time.
Data Use and Services Maturity Matrix	Ranks the maturity of nine components of data on a scale of 1 (least mature) to 5 (most mature).	Earth science community/earth science and climate data	Alleviate burden of data stewards, reduce incompatibility of stewardship maturity assessment results from individually defined models, and provide a unified and holistic view of stewardship practice maturity.

93 About Data Stewardship Wizard https://ds-wizard.org/about.html.

94 RDA and World Data System (WDS) joint working group criteria. https://www.rd-alliance.org/group/wdsrda-assessment-data-fitness-use-wg/outcomes/wdsrda-assessment-data-fitness-use-wg-outputs.

95 CoreTrustSeal is a nonprofit organization that promotes trustworthy and sustainable data infrastructures through its certification process. https://www.coretrustseal.org. CoreTrustSeal replaced the DSA (which was originally funded/developed by DANS as a certification tool for data infrastructures).

Table A-3: Assessed Tools; Approach to Measurement of FAIRness

Assessment Tool Name	Adherence to Original FAIR Principles	# of F Criteria Measured (out of 4)	# of A Criteria Measured (out of 4)	# of I Criteria Measured (out of 3)	# of R Criteria Measured (out of 4)	Other Criteria Measured
DANS Fairdat	Yes	3	1	2	3	None
DANS FAIR Enough?	Yes	2	0	3	4	2
FAIR Evaluator	Yes	4	3	3	3	None
ANDS-NECTAR RDS FAIR Data Assessment Tool	Yes	3	2	1	2	1
WMO-Wide Stewardship Maturity for Climate Data	No	2	1	2	3	4
CSIRO 5-Star Data Rating Tool	Yes	3	1	2	3	1
Stewardship Maturity Matrix	No	1	1	0	2	2
FAIR Metrics Questionnaire	Yes	3	3	3	3	None
Data Stewardship Wizard	Yes	0	0	1	1	2
Checklist for Evaluation of Dataset Fitness for Use	Yes	2	0	1	4	1
RDA-SHARC Evaluation	Yes	3	1	1	3	1
Data Use and Services Maturity Matrix	No	1	0	0	1	None

Table A-4: Assessed Tools; Evaluation of Applicability to and Use in CEDAR Project

Assessment Tool Name	Tool Limitations	Distinct Features	Impact on CEDAR
DANS Fairdat	The tool is a prototype, currently built in SurveyMonkey, with limited functionality, and assesses only three FAIR facets.	Precursor tool still in prototype stage.	This tool used a simple formula to calculate overall FAIR, which can provide an exemplar for an objective ultimate assessment.
DANS FAIR Enough?	Evaluation of the trustworthiness of the data repository based on the CoreTrustSeal 16 minimum core requirements, which may not be relevant to CEDAR.	Inclusion of a question specific to repository trustworthiness. Some of the criteria depend on use of CoreTrustSeal certified repositories.	Evaluation of trustworthiness of a repository could be useful for future incorporation of additional repositories.
FAIR Evaluator	Evaluates FAIRness of resources (individual artifacts) rather than entire repositories (e.g., databases).	The tool offers pass/fail responses and provides explanations for fail responses. The tool evaluates the FAIRness of resources (individual artifacts) rather than entire repositories.	Data resources may still be FAIR even if they "fail" an assessment. Its evaluation of resources rather than entire repositories could pose difficulty to CEDAR when deciding what resources to evaluate. CEDAR must take into account the FAIRness of the repositories overall.
ANDS-NECTAR RDS FAIR Data Assessment Tool	The questions have drop-down choices for answers; the scope of the potential answers may limit the tool.	The tool accounts for situations in which data cannot be made openly accessible (e.g., there are privacy or national security concerns that would limit access) and proprietary data—in the context of reusable.[96]	This tool offers considerations for managing datasets that also contain data that must not be shared broadly. The tool also embeds explanations of each term and questions, should a user need additional information. Manual questionnaire allows flexibility that CEDAR can use when developing its own assessment.

[96] https://www.ands.org.au/working-with-data/sensitive-data.

Assessment Tool Name	Tool Limitations	Distinct Features	Impact on CEDAR
WMO-Wide Stewardship Maturity for Climate Data	Because the tool focuses on maturity assessment in preparation for inclusion of a data set in the WMO Catalogue of Climate Data, it is very domain-specific. The matrix concentrates on data management and stewardship practices employed for a dataset, less on data management and the underlying science.[97]	Focuses solely on climate data and opts to present minimal criteria to evaluators: data access, usability and usage, quality management, and data management.	As a matrix tool that assesses the maturity of digital data across components identified in its domain, it focuses on data management. CEDAR could determine where its FAIR assessment would be of most value depending on future users and the level of control such users have over the datasets.
CSIRO 5-Star Data Rating Tool	No explanation is provided to understand the criteria or responses, which may limit adaptation of the tool to other domains.	Incorporates an evaluation of the trustworthiness of data by assessing how the data are used, by whom, how many times, and whether the data experience scheduled maintenance updates. Also assesses data projects (i.e., whether the project is complex, interdisciplinary, or cross-organizational).	Demonstrates use of other data criteria in additional to the FAIR principles, such as "updated/maintained" or "trusted," when analyzing the data. Questions are subjective and could be interpreted differently.
Stewardship Maturity Matrix	This tool does not directly align with the FAIR guiding principles, though there are aspects of FAIR assessed within this tool (e.g., accessibility, preservability). The tool's terminology derives from other maturity indices.	Maturity model that establishes its own set of nine key data components: preservability, accessibility, usability, production sustainability, data quality assurance, data quality control/monitoring, data quality assessment, transparency/traceability, and data integrity.	Matrix tool assesses the maturity of digital data across nine components in its specific domain. This tool's testing of metadata against the maturity indicators can be used when developing CEDAR-specific criteria.
FAIR Metrics Questionnaire	The tool is an exemplar and intended to be adapted to specific domains. At times, evaluators of the tool indicated that certain questions or responses were hard to understand.[98] Metrics in this initiative are in a constant state of flux/debate.	Fourteen exemplar, universal metrics are based on each of the FAIR subprinciples; links are provided to each of the subprinciples.	This tool provides general descriptions of what, why, and how digital resources can be assessed for FAIRness and is derived from the originators of the principles. It can provide a starting point for a distinct tool.

[97] https://figshare.com/articles/journal_contribution/The_manual_for_the_WMO-Wide_Stewardship_Maturity_Matrix_for_Climate_Data/7002482.

[98] https://www.nature.com/articles/sdata2018118.

Assessment Tool Name	Tool Limitations	Distinct Features	Impact on CEDAR
Data Stewardship Wizard	The tool does not provide detail into the methodology and criteria it uses for evaluation. The tool reports provide a tailored assessment of FAIRness and suggest areas for improvement.	Provides guidance on data stewardship, collaboration, and storage for commercial end users.	The tool is an adaptive questionnaire and selects questions based on prior answers. These questions also include structured follow-up questions generated by the wizard; the answers are structured and can be incorporated back into the tool (e.g., the wizard can add up data storage information collected in multiple answers to provide the total data storage requirements). This tool focuses on the FAIRness of the data and the maintenance of the data over time.
Checklist for Evaluation of Dataset Fitness for Use	Not applicable to non-CoreTrustSeal-certified repositories. Intended for manual implementation and may not be scalable for repositories with many datasets; evaluators must be experienced with the dataset. The checklists may not be specific to research domains that do not have established data or metadata standards for reusability.	A fifth category of fitness-for-use criteria focuses on data curation, which the working group describes as leading to overall FAIRness.	The checklist focuses on the repository manager perspective, but not the data user. Not likely that many repositories that could be integrated into CEDAR are CoreTrustSeal certified. Curation measurement may be important for future iterations of a CEDAR tool, but is not directly related to FAIR facets.
RDA-SHARC Evaluation	Simplified self-assessment grid focuses only on essential criteria; the originators deem the more extensive grid is not possible for most scientists. It is also not sufficient to serve as a comprehensive assessment of the FAIRness of data practices.	Presents a checklist framed as “never, if mandatory, sometimes, always” for different aspects of F, A, I, R. One set of criteria in the checklist—“motivations for sharing”— distinct from other tools.	Could be applied to CEDAR by (1) drafting tool for wide variation in data science knowledge, and (2) including additional criteria to explore motivations for sharing data.

Assessment Tool Name	Tool Limitations	Distinct Features	Impact on CEDAR
Data Use and Services Maturity Matrix	The tool is not based on FAIR and is specific to best practices developed and used in the environmental science community.	Uses a scale to evaluate the level of data maturity across a specific set of maturity matrix components. Unique components include a focus on data impact (whether decisions are made based on the data), customer service, and customer engagement.	Not feasible for direct application to CEDAR given the deviation from FAIR, but could apply the scale used to evaluate maturity and its applicability to evaluating FAIRness.

A domain-specific assessment tool for application to the CEDAR reference implementation (RI) and the PCOR domain is currently under development. This development will integrate information and lessons learned from the FHIR4FAIR track at the January 13–15, 2021, Health Level 7 (HL7®) Fast Health Interoperability Resources (FHIR®) Connectathon[99] as well as the EU's FAIR4Health initiative.[100]

[99] https://confluence.hl7.org/display/FHIR/2021-01+FAIR.

[100] FAIR4Health, https://www.fair4health.eu/.

Appendix B Other Resources Researched

The initial AHRQ CEDAR reference implementation is intended to integrate several specifically identified CEPI repositories that contain PCOR findings.[101] Other repositories not specifically identified for integration into the CEDAR RI can inform RI development and could be considered for future integration to provide even more robust access to information critical to clinical decision support (CDS) and healthcare decision making. The environmental scan catalogs other projects, repositories, and resources related to PCOR (both internal and external to AHRQ) that provide insights into current development, or that could be connected to or inform CEDAR in the future.

First cataloged and found in Table B-1 were PCOR resources from AHRQ's Library of PCOR resources, which were evaluated for openness of access, content type, considerations that could inform development of or impact integration into CEDAR, specific identification as relevant to PCOR, and timeliness of included products. Also reviewed was the balance across types of PCOR products (e.g., systematic reviews and clinical trials), balance across end users, and the number of products offered in the resource. Tables B-2 and B-3 list the results of additional research that broadened the scope of assessment into 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.

Table B-1. Additional Repositories Reviewed for Potential CEDAR Integration Derived from AHRQ's Library of PCOR Resources[102]

Repository	Freely Accessible?	Description	Considerations for CEDAR[103]	Specific PCOR Focus	Timeliness
PCORI® Research and Results Database®[104]	Yes	Searchable, filterable repository of PCORI-funded project results	Low volume of products	High	High
Cochrane Library Database of Systematic Reviews[105]	Yes, depending	Searchable repository of systematic reviews	Some reports may be subject to paywalls or other restrictions	Medium	High
AHRQ Project Research Online Database[106]	Yes	Searchable repository of AHRQ research projects	Project pages may vary in information contained	Medium	High

[101] The original tasking for the initial CEDAR RI requires integration of the Effective Health Care Program, Evidence-based Practice Centers and the Systematic Review Data Repository, the National Guideline Clearinghouse, the U.S. Preventive Services Task Force, and CDS Connect.

[102] https://www.ahrq.gov/pcor/library-of-resources/index.html.

[103] These considerations may be revisited after stakeholder engagement.

[104] https://www.pcori.org/research-results

[105] https://www.cochranelibrary.com/cdsr/about-cdsr

[106] https://digital.ahrq.gov/ahrq-funded-projects/search

Repository	Freely Accessible?	Description	Considerations for CEDAR[103]	Specific PCOR Focus	Timeliness
GradePro Database of GRADE EtDs and Guidelines[107]	Yes	Searchable database of guidelines (login required)	Depends on ease of integration	Medium	Unclear
HSRProj (Academy Health)[108]	Yes	Repository of current and recently completed funded health services research projects	May not be of benefit to all users	Low	Unclear
HSRIC (NIH)[109]	Yes, depending on resource	Searchable, browsable repository of health services research resources, including data, and topics; links to HSRProj	May need to find a way to filter data for integration into CEDAR; links out to multiple other websites and resources	Medium	Unclear
Clinicaltrials.gov	Yes	Database of privately and publicly funded clinical studies	High, but not domain-specific	Low	High
PubMed®[110]	Yes, although not all articles are fully available	Citations for biomedical literature	High volume of products and high comprehensiveness Primarily used by researchers Some content subject to paywalls.	Low	High
Research Portfolio Online Reporting Tool (RePORT)[111]	Yes	Provides access to reports, data, and analyses of NIH research activities	Information about projects funded by NIH (citations, expenditures, etc.) ExPORTER tool provides exemplar for bulk download of project details	Low	High
JBI Systematic Review Register[112]	Yes, includes only titles and abstracts	International register of ongoing systematic reviews	Includes only titles and abstracts; integration may require investigation of metadata and FAIRness	Medium	Unclear

[107] https://gradepro.org/guidelines/

[108] https://academyhealth.org/about/programs/hsrproj

[109] https://hsric.nlm.nih.gov/hsric_public/

[110] https://pubmed.ncbi.nlm.nih.gov/

[111] https://report.nih.gov/

[112] https://joannabriggs.org/systematic-review-register

Repository	Freely Accessible?	Description	Considerations for CEDAR[103]	Specific PCOR Focus	Timeliness
VA Evidence Synthesis Program Reports[113]	No, embargoed and archived reports	Intended to provide access to syntheses of targeted health topics of importance to the VA	Reports may at times be embargoed, which can impede timely access; focus is primarily on VA population	Medium	Medium

Figure B-1 depicts the scope of the research and the wider net to capture information sources that were researched. In the two outer circles, in particular, the scan considered various types of sources, including but not limited to specialty societies, organizations maintaining generalist data repositories, patient safety sources, patient-reported outcome sources, quality measurement sources and organizations, population/community health resources, clinical and cost effectiveness guidance, and clinical and other practice guidelines. Generalist data repositories were informative for their approaches to data ingest, given the potentially broad scope of data and artifacts, and guidance offered to data contributors to maintain well-stewarded repositories.

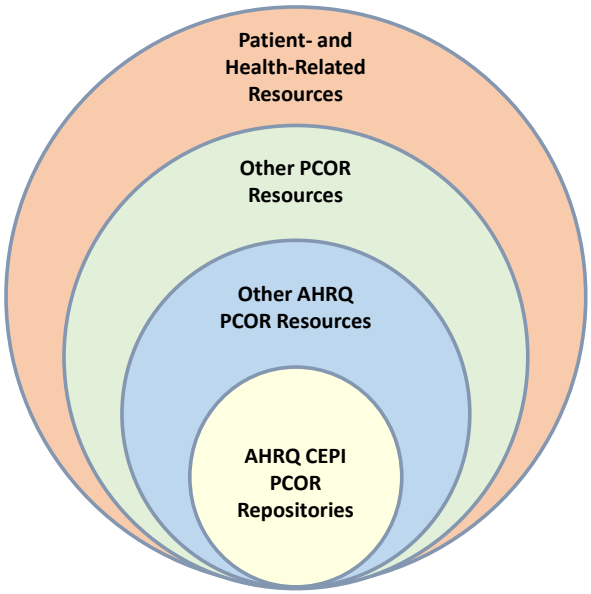

Figure B-1. Depiction of PCOR and Health-Related Repository Research

If of interest, future inclusion of these other resources and repositories could follow different pathways. The CEDAR RI could incorporate additional repositories, but there could also be procedures to allow repositories to actively engage and connect to the RI. Such procedures could include:

- Self-evaluation of connectivity appropriateness using the criteria developed in this report
- Self-evaluation of data and repository FAIRness using the CEDAR FAIR assessment tool

[113] https://www.hsrd.research.va.gov/publications/esp/reports.cfm

- Development of repository indexers for AHRQ consideration, aligning with published CEDAR indexer standard(s), data models, vocabularies, and metadata standards

B.1 Other Projects Engaged in CEDAR-Like Initiatives

The environmental scan also reviewed projects (both internal and external to AHRQ) engaged in CEDAR-like initiatives to identify, to the extent possible, lessons learned or other information useful to CEDAR development. Although more projects are expected to be assessed for lessons learned and potential collaboration over the course of the project's period of performance, the scan reviewed the following:

- **Mobilizing Computable Biomedical Knowledge (MCBK).** MCBK is a public-private partnership to create an open standards-based ecosystem that supports robust and unbiased methods to expose the currency, validity, and provenance of computable biomedical knowledge.[114] This effort is also creating and supporting a method to transition knowledge from human-readable to fully computable form.
- **ACTS Initiative.** The AHRQ evidence-based Care Transformation Support (ACTS) Initiative began in 2018. Initially, it sought to build a roadmap to ensure that AHRQ's evidence, guidance, resources, and tools are: compatible with resources and tools from other organizations; FAIR (Findable, Accessible, Interoperable, Reusable); computable; and useful.[115] More information on the ACTS Initiative is included in Appendix D.
- **Patient Access APIs.** In 2020, the Office of the National Coordinator for Health Information Technology and the Centers for Medicare & Medicaid Services finalized complementary regulatory provisions requiring the implementation of APIs that allow providers and certain payers to send, at patients' request, patient health information to third-party applications of patients' choosing.[116] The purpose of the API is to simplify patients' ability to collect copies of their health information. The API must be FHIR based. These requirements and any resulting uptick in the use of third-party applications may be of use and interest to CEDAR, especially for a patient use case.
- **FAIR4Health.** This project seeks to facilitate the European Union Health Research community's efforts to FAIRify, share, and ultimately reuse datasets derived from publicly funded research initiatives.[117] The FAIR4Health FAIRification Plan is a four-step process that includes (1) strategic outreach across the EU, (2) development of guidelines for a FAIR data certification roadmap, (3) development of a user-centered FAIR4Health platform, and (4) implementation of this platform within case studies to test value and impact around health research and outcomes.[118]

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114 University of Michigan, Mobilizing Computable Biomedical Knowledge, https://mobilizecbk.med.umich.edu/home.

115 AHRQ, AHRQ evidence-based Care Transformation Support, https://digital.ahrq.gov/acts.

116 Final Rule, 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program, 85 FR 47099 (August 4, 2020), and Final Rule, Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Interoperability and Patient Access, 85 FR 25510 (May 1, 2020).

117 https://www.fair4health.eu/en/project#.

118 Id.

- **Fair Data Informatics Lab.** The FAIR Data Informatics Lab at the University of California San Diego has developed a range of tools and strategies for researchers to align their biomedical research with FAIR Data Principles.[119] One tool, the SciCrunch® Infrastructure Discovery Portal, enables federated searching across over 300 biomedical databases.

[119] FAIR Data Informatics Lab, https://www.fdilab.org/.

Tables B-2 and B-3 describe additional repositories for CEDAR integration.

Table B-2. Other Outcomes or Health-Related Data Repositories (Federal)

Federal Initiative and URL	Repository Name/ Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?	Identified Standards or Formats	Description
The Cancer Genome Atlas Program https://portal.gdc.cancer.gov	The Cancer Genome Atlas	Yes + Restricted Access	Yes	Variable + multiple applications (API, etc.)	Data-driven platform allowing the search and download of cancer data for analysis
CDC Chronic Disease and Health Promotion Data & Indicators https://chronicdata.cdc.gov	Chronic Data	Yes	Yes	Socrata Open Data (SODA) API	CDC Chronic Disease and Health Promotion Data & Indicators contain datasets involving leading indicators and risk factors for chronic diseases
CDC Data Catalog https://data.cdc.gov/browse	Data Catalog	Yes	Yes	SODA API	The CDC Data Catalog sorts datasets by category, type, and tags
CDC National Center for Health Statistics, National Health and Nutrition Examination Survey (NHANES)	NHANES Datasets	Yes + Restricted Access	Yes	SAS/xpt	Data from studies (interviews and physical examinations) assessing the nutritional status and health of children and adults in the United States
CDC State Tobacco Activities Tracking and Evaluation (STATE) System https://www.cdc.gov/statesystem/	STATE System	Yes	Yes	CSV; PDF	CDC State Tobacco Activities Tracking and Evaluation (STATE) System is an interactive application containing State-level data on tobacco use, prevention, and control.
CDC STATE System/Tobacco Data Use Portal https://chronicdata.cdc.gov/browse?category=Tobacco+Use	Tobacco Use Data Portal	Yes	Yes	SODA API	Provides expanded datasets related to tobacco use as part of the CDC STATE System. Data export offered in multiple formats via the SODA API.
Centers for Medicare & Medicaid Services' Measures Inventory Tool https://cmit.cms.gov/CMIT_public/ListMeasures	Measures Inventory Tool	Yes	Yes	HTML; PDF	Repository of information about quality measures used in programs managed by the Centers for Medicare & Medicaid Services
FDA Adverse Event Reporting System https://www.fda.gov/drugs/questions-and-answers-fdas-adverse-event-reporting-system-faers/fda-adverse-event-reporting-system-faers-public-dashboard	FDA Adverse Event Reporting System - Public Dashboard and Data Files	Yes	Yes	ASCII; XML	Data repository of adverse drug events compiled from case reports

Federal Initiative and URL	Repository Name/ Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?	Identified Standards or Formats	Description
Health Resource & Services Administration (HRSA) https://data.hrsa.gov/	Data.HRSA.gov	Yes	Yes	Multiple (CSV, SAS, etc.)	Searchable data repository compiling data and maps from healthcare programs HRSA supports
OpenFDA https://open.fda.gov/	OpenFDA	Yes	Yes	API; JSON	Open-source repository and API of FDA-related datasets
NIH Genomic Data Commons https://portal.gdc.cancer.gov/	Data Portal	Yes + Restricted Access	Yes	GDC API; JSON	Harmonized cancer datasets available in a variety of ways, including a data portal, website, and API Data searchable by format, including other ways, with identification of number of files in each type of format
NIH National Institute of Allergy and Infectious Disease (NIAID) https://www.niaid.nih.gov/research/accessing-clinical-data	NIAID Clinical Trials Repository	Restricted Access	Yes	FAIR Data Principles	Repository of biomedical and health data to accelerate development of interventions, diagnostics, improved prevention strategies, disease surveillance
Substance Abuse and Mental Health Services Administration (SAMHSA) https://www.samhsa.gov/data/	Data and Dissemination	Yes	Yes	Multiple (HTML, PDF, etc.)	Resources available include data files, codebooks, and datasets related to national substance abuse and mental health research data

Table B-3. Other Outcomes or Health-Related Data Repositories (State and Non-Governmental Organization)

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
AABB https://www.aabb.org/news-resources/resources/clinical-resources	Clinical Guidelines	Yes + Restricted Access	Yes	PDF	Clinical guidelines and evidence on use of transfusions

[120] For purposes of this table, "timely" means at the time of review, the repository indicated it contained data or artifacts dated 2017 or later. Repositories may also contain data that is older than 2017.

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
Academy of Breastfeeding Medicine https://www.bfmed.org/protocols	Protocols	Yes	Yes	PDF	Protocols for facilitating best practices in medicine Not all are recently updated, and review date not indicated
Academy of Nutrition and Dietetics https://www.eatrightpro.org/research/applied-practice/evidence-analysis-library	Evidence Analysis Library	Restricted Access (Members)	Undetermined	Undetermined	Systematic reviews and evidence-based nutrition practice guidelines for the healthcare team
AIM Specialty Health https://aimspecialtyhealth.com/resources/clinical-guidelines/	Clinical Guidelines	Yes	Yes	PDF	Guidelines offered in conjunction with health efficiency consulting services; guidelines range from cardiology to sleep to oncology
Alliance for the Implementation of Clinical Practice Guidelines https://aicpg.org	Clinical Guidelines	Yes	Undetermined	HTML	Searchable archive of NGC summaries; AiCPG guidelines described as “coming soon” (undetermined whether those will be freely accessible)
Alzheimer's Association https://www.gaaindata.org/partners/online.html	GAAIN Data Repository	Restricted Access	Yes	Multiple/depends on data contributor	Data repository incorporating data from 54 global partners contributing data; must apply for access.
Alzheimer's Association https://www.alz.org/research/for_researchers/partnerships/wwadni/about_wwadni	WW-ADNI	Yes	Yes	Undetermined	Data from PET and MRI scans made available to the scientific community at no cost for use in designing or evaluating research
American Academy of Dermatology https://www.aad.org/member/clinical-quality/guidelines	Clinical Guidelines	Yes	Yes	HTML, PDF	Dermatology guidelines that are current or in development

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
American Academy of Family Physicians https://www.aafp.org/family-physician/patient-care/clinical-recommendations/recommendations-by-topic.html	Clinical Recommendations	Yes	Yes	HTML	Links to USPSTF and other resources; evidence-based guidance about preventive care, diagnosis and assessment, and management of acute and chronic conditions
American Academy of Neurology https://www.aan.com/Guidelines/Home/ByStatusOrType?status=all	Clinical Guidelines	Yes	Yes	GRADE (Grading of Recommendations Assessment, Development, and Evaluation)	Clinical guidelines related to neurology, including guidelines recently updated and guidelines open for public comment
American Academy of Ophthalmology https://www.aao.org/iris-registry/data-analysis/requirements	IRIS® (Intelligent Research in Sight) Clinical Data Registry	Restricted Access	Yes	Undetermined	Clinical data registry used for MIPS reporting that also offers aggregated de-identified data for research purposes
American Academy of Orthopaedic Surgeons https://www.aaos.org/registries/registry-program/american-joint-replacement-registry/	American Joint Replacement Registry	Restricted Access	Undetermined	Undetermined	Data on knee and hip replacement procedures that falls into three data types: procedural, post-operative, and patient-reported outcomes, and provided to researchers via the Registry Analytics Institute
American Academy of Orthopaedic Surgeons http://www.orthoguidelines.org/	Orthoguidelines	Yes	Yes	PDF	Clinical guidelines related to orthopedics ranging from 2011 to 2020
American Academy of Otolaryngology https://www.entnet.org/content/clinical-practice-guidelines	Practice Management Resources	Yes	Yes	HTML, PDF	Clinical guidelines, expert consensus statements, position statements relevant to ENTs
American Academy of Pediatrics https://brightfutures.aap.org/Pages/default.aspx	Bright Futures	Viewable	Yes	PDF	Guidelines, screening tools, periodicity schedules, etc., for pediatricians

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
American Academy of Pediatrics https://redbook.solutions.aap.org/redbook.aspx	Red Book®	Restricted Access (Members)	Yes	PDF	Clinical guidelines on pediatric infectious disease
American Academy of Physical Medicine and Rehabilitation https://www.aapmr.org/quality-practice/evidence-based-medicine/clinical-practice-guidelines	Clinical Practice Guidelines	Yes	Yes	HTML, PDF	Browsable repository of current and archived clinical practice guidelines endorsed by the association
American Academy of Physical Medicine and Rehabilitation https://now.aapmr.org/	PM&R Knowledge NOW®	Yes	Yes	HTML	PM&R Knowledge NOW is a resource for physicians and patients providing an overview of conditions and treatments in the specialty of physical medicine and rehabilitation
American Association for Respiratory Care https://www.aarc.org/resources/clinical-resources/clinical-practice-guidelines/	Clinical Practice Guidelines	Yes	Yes	PDF	Browsable repository of clinical practice guidelines; references NGC
American Association of Clinical Endocrinologists https://pro.aace.com/resources?keys=&field_disease_state_content_t_value%5BGuidelines%5D=Guidelines	Clinical Practice Guidelines	Yes	Yes	PDF	Searchable repository of clinical practice guidelines; also offers disease state resources with guidelines, algorithms, and other tools specific to distinct diseases
American Association of Neurological Surgeons https://www.americanspineregistry.org/	American Spine Registry	Restricted Access	Yes	Undetermined	Quality improvement registry for spine care that offers data reuse, including access to patient-reported outcomes data
American Association of Neuromuscular and Electrodiagnostic Medicine (AANEM) https://www.aanem.org/Practice/Guidelines	Guidelines	Yes	Yes	HTML, PDF	Guidelines and consensus statements for the assessment and treatment of muscle and nerve disorders
American Association of Neuroscience Nurses http://aann.org/publications/clinical-practice-guidelines	Clinical Practice Guidelines	Yes	Yes	PDF	Evidence-based practice guidelines for nursing management of specific patient populations with neurological injuries

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
American Cancer Society https://www.cancer.org/cancer.html	Cancer A-Z	Yes	Yes	HTML, PDF	Basic information about cancer and its causes; in-depth information on specific cancer types
American Cancer Society https://canceratlas.cancer.org/	The Cancer Atlas	Yes + IP Restrictions	Yes	PDF, xlsx	Overview of global cancer incidence and care offering downloadable datasets, originally sourced from WHO reports
American Cancer Society https://www.cancer.org/treatment.html	Treatment & Support	Yes	Yes	Web entries, PDFs, web links	Patient-focused repository on treatment options, side effects, and insurance issues
American Clinical Neurophysiology Society https://www.acns.org/practice	Practice Resources	Yes + Member Resources	Yes	HTML, PDF	ACNS practice resources include: COVID-19 Resources, Guidelines and Consensus Statements, Practice-related Resources, Coding and Reimbursement
American College of Allergy, Asthma, and Immunology https://acaai.org/asthma	Practice Resources – Asthma	Yes	Yes	Web entries with links	Asthma resources include: Asthma 101, Asthma Symptoms, Asthma Testing and Diagnosis, Asthma Treatment, etc.
American College of Allergy, Asthma, and Immunology https://acaai.org/allergies	Practice Resources – Allergies	Yes	Yes	Web entries with links	Allergy resources include: Types of Allergies, Allergy Treatments, Anaphylaxis, etc.
American College of Cardiology/ACC Foundation https://www.acc.org/Guidelines	Clinical Guidelines	Yes	Yes	Web entries with links, HTML, PDF	Evidence-based clinical statements and guidelines in the field of cardiovascular medicine
American College of Chest Physicians https://www.chestnet.org/Guidelines-and-Resources	Guidelines & Resources	Yes	Yes	HTML, PDF, audio recordings	Repository of clinical guidelines
American College of Emergency Physicians https://www.acep.org/by-medical-focus/	Practice: By Medical Focus	Yes	Yes	PDF, web links	Resources for 20 medical focus areas
American College of Gastroenterology https://gi.org/guidelines/	Guidelines	Yes	Yes	Web entries with links to external sources	ACG Guidelines and other Clinical Documents consist of published journal entries and publications, as well as guidelines that are in the publication process

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
American College of Occupational and Environmental Medicine https://acoem.org/Practice-Resources/Practice-Guidelines-Center/MDGuidelines%C2%AE	Clinical Guidelines	Restricted Access (Subscription)	Yes	PDF	Links to PDF guidance documents ACOEM offers a summary version of the guidelines for free
American College of Physicians https://www.acponline.org/clinical-information	Clinical information	Yes	Yes	Weblinks, PDF, app (guidelines)	Clinical guidelines and recommendations, performance measures, journals and publications, clinical resources, and products; clinical guidelines offer links to accompanying patient materials
American College of Preventive Medicine https://www.acpm.org/education-events/practice-guidelines/	Practice Guidelines	Yes	Yes	PDF	Links to guidelines across clinical disciplines
American College of Rheumatology RISE Registry https://www.rheumatology.org/Practice-Quality/RISE-Registry	Practice and Quality – RISE registry	Yes + Restricted Access	Undetermined	Undetermined	Electronic health record (EHR)-enabled rheumatology registry Data sent to data analytic centers for analysis
American College of Rheumatology Clinical Practice Guidelines https://www.rheumatology.org/Practice-Quality/Clinical-Support/Clinical-Practice-Guidelines	Clinical Practice Guidelines	Yes	Yes	PDF, also available in an app	Lists ACR clinical practice guidelines with links to PDFs
American Dental Association https://ebd.ada.org/en/evidence/guidelines	Clinical Practice Guidelines	Yes	Yes	Links to web entries, PDFs	Includes links to clinical practice guidelines for dentists
American Diabetes Association https://diabetes.org/resources	Resources	Yes	Undetermined	Web entries, links to PDFs, other	Includes resources for patients and clinicians
American Diabetes Association https://professional.diabetes.org/research-grants	Research and Grants	Yes	Yes	Web entries, links to PDFS	Includes links and information on grant opportunities

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
American Epilepsy Society https://www.aesnet.org/clinical_resources/guidelines	Guidelines	Yes	Yes	PDF	Includes links to guidelines
American Epilepsy Society https://www.aesnet.org/clinical_resources/practice_tools	Practice Tools	Yes + Restricted Access	Yes	Web entries, PDF	Includes links to tools for patient assessments and care
American Gastroenterological Association https://gastro.org/guidelines/#	Clinical Guidelines	Yes	Yes	GRADE	A repository of evidence-based guidelines based on systematic reviews of the medical literature
American Geriatrics Society (AGS) https://geriatricscareonline.org/ProductTypeStore/clinical-guidelines-recommendations/8/	Guidelines, Recommendations, and Position Statements	Yes + Restricted Access	Yes	Web links, HTML, PDF	AGS guidelines, recommendations, and position statement resources
American Headache Society https://americanheadachesociety.org/resources/guidelines/	Clinical Guidelines	Yes	Yes	HTML, PDF	Clinical practice guidelines for diagnosing and treating neurological diseases
American Heart Association https://www.heart.org/en/health-topics	Patient Information	Yes	Yes	HTML, audio files	Searchable index of resources for patients (pre- and post-diagnosis)
American Heart Association https://professional.heart.org/en/guidelines-and-statements/guidelines-and-statements-search	Clinical Guidelines	Yes	Yes	PDF, ePub	Searchable repository of clinical practice guidelines
American Heart Association https://precision.heart.org/	AHA Precision Medicine Platform	Restricted Access (registration)	Yes	Jupyter notebooks, data format undetermined	Cloud-based platform offering streamlined access to datasets, data harmonization, and analytics tools Workspaces available for a fee
American Medical Association https://edhub.ama-assn.org/clinical-topics	Ed Hub/Clinical Topics	Restricted Access	Yes	HTML, PDF, audio files	Browsable repository of information on clinical topics, including guidelines; links to USPSTF

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
American Occupational Therapy Association https://www.aota.org/Practice/Researchers.aspx	Evidence-based Practice & Research	Yes + Restricted Access	Yes	Weblinks, HTML	Resources to help members find and use clinically relevant literature
American Optometric Association https://www.aoa.org/practice/clinical-guidelines/clinical-practice-guidelines?sso=y	Clinical Practice Guidelines	Yes	No	Web links, PDF	Optometric guidelines in this repository are under revision as of January 2021
American Psychiatric Association https://www.psychiatry.org/psychiatrists/practice/clinical-practice-guidelines	Clinical Practice Guidelines	Yes	Yes	Web links, PDF	Evidence-based recommendations for the assessment and treatment of psychiatric disorders
American Society for Colposcopy and Cervical Pathology https://www.asccp.org/guidelines	Clinical Guidelines	Yes	Yes	HTML, app (iOS and Android)	Browsable directory of cervical cancer screening and management information; links to USPSTF.
American Society for Gastrointestinal Endoscopy https://www.asge.org/home/resources/key-resources/tech-assessments	Technology Assessments	Yes	Yes	HTML, PDF	Reviews of emerging technology used in GI practice based on literature reviews and crosschecks against FDA adverse event database
American Society for Gastrointestinal Endoscopy https://www.asge.org/home/resources/key-resources/guidelines	Clinical Guidelines	Yes	Yes	GRADE, HTML	Browsable repository of clinical practice guidelines
American Society for Metabolic and Bariatric Surgery https://asmbs.org/resource-categories/guidelines-recommendations	Guidelines	Restricted Access (Membership)	Yes	Undetermined	Clinical practice guidelines
American Society for Parenteral and Enteral Nutrition http://www.nutritioncare.org/guidelines_and_clinical_resources/	Guidelines and Clinical Resources	Yes + Restricted Access (ASPEN login)	Yes	Web links, PDF	Guidelines, publications, and clinical resources for nutritional care

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
American Society for Radiation Oncology https://www.astro.org/Patient-Care-and-Research/Clinical-Practice-Statements/Clinical-Practice-Guidelines	Clinical Practice Guidelines	Yes	Yes	PDF	Browsable repository of clinical guidelines
American Society for Reproductive Medicine https://www.asrm.org/news-and-publications/practice-committee-documents/	Practice Committee Documents	Yes	Yes	Web links, PDF	Browsable repository of guidelines and other clinical practice resources
American Society of Anesthesiologists https://www.asahq.org/standards-and-guidelines	Guidelines, Statements, Clinical Resources	Yes	Yes	Web links, PDF	Repository including standards, practice guidelines, expert consensus documents, and other clinical resources
American Society of Breast Surgeons https://www.breastsurgeons.org/resources/statements	Official Statements	Yes	Yes	PDF	Repository of resources including consensus guidelines and practice guidelines
American Society of Clinical Oncology https://www.asco.org/research-guidelines/center-research-analytics-centra/asco-data-library	ASCO Data Library	Restricted Access	Undetermined	Web links, PDF, xls, CSV	Connections to various oncology-focused data registries, including CancerLinq®, Glioblastoma Clinicogenomics Data, National Cancer Opinion Survey, etc.
American Society of Clinical Oncology https://www.asco.org/research-guidelines/quality-guidelines/guidelines	Guidelines, Tools, & Resources	Yes	Yes	Web links, HTML, PDF, iOS/Android app	Repository including clinical practice guidelines, provisional clinical opinions (PCOs), and guideline endorsements
American Society of Colon and Rectal Surgeons https://fascrs.org/healthcare-providers/education/clinical-practice-guidelines	Clinical Guidelines	Yes	Yes	PDF	Browsable repository of published clinical practice guidelines
American Society of Echocardiography https://www.asecho.org/guidelines-search/	Clinical Guidelines	Yes	Yes	PDF	Searchable repository of clinical guidelines
American Society of Echocardiography https://imageguideregistry.org/echo-2/	ImageGuideEcho™	Restricted Access	Yes	Undetermined	Repository of quality metrics and patient outcomes data and data analysis; serves a reporting function

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
American Society of Health-System Pharmacists https://www.ashp.org/Drug-Shortages	Drug Shortages	Yes	Yes	HTML, API (JSON)	Information on new and resolved drug shortages, including information offered via the Drug Shortages API
American Society of Health-System Pharmacists https://www.ashp.org/Pharmacy-Practice/Policy-Positions-and-Guidelines/Browse-by-Topic	Clinical Guidelines	Yes	Yes	PDF	Browsable repository of published clinical practice guidelines
American Society of Health-System Pharmacists https://www.ashp.org/Pharmacy-Practice/Resource-Centers/ASHP-Forecasts	ASHP Forecasts	Restricted Access (membership)	Yes	Undetermined	Forecasting reports in interactive data visualizations focused on drug spending and pharmacy practice forecasts
American Society of Hematology https://www.hematology.org/research/gene-table	Gene Variants in Heme Malignancies Table	Yes	Yes	Web links, HTML	Interactive table offering gene variant information
American Society of Interventional Pain Physicians https://asipp.org/ipm-practice-guidelines/	Practice Guidelines	Yes	No	PDF	Repository of guidelines
American Society of Plastic Surgeons https://www.thepsf.org/research/registries/graft	GRAFT	Restricted Access (membership)	Yes	iOS/Android app	Registry of fat grafting incidence and outcomes
American Thoracic Society https://www.thoracic.org/statements/index.php	Statements, Guidelines, & Reports	Yes	Yes	GRADE	Guidelines developed using GRADE; browsable collection of links to guidelines in different clinical areas, as well as other information
American Thyroid Association https://www.thyroid.org/professionals/ata-professional-guidelines/	Guidelines	Yes	Yes	PDF	Browsable repository of published clinical practice guidelines

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
American Urological Association Education and Research https://www.auanet.org/research/research-resources/data-and-statistical-services/data-sources	Census Public Use Micro Dataset	Restricted Access	No	Undetermined	Information on a representative sample of urologists; links to other databases, and ability to request assistance with integrating data
Association for Molecular Pathology https://www.amp.org/clinical-practice/practice-guidelines/	Clinical Guidelines	Yes	Yes	PDF	Browsable repository of published clinical practice guideline
Association for Professionals in Infection Control and Epidemiology https://apic.org/professional-practice/implementation-guides/#implementaion-guide-7463	APIC Implementation Guides	Restricted Access (registration)	Yes	Undetermined	Evidence-based strategies for surveillance and elimination of infection with links to online tools and resources
Association for Radiologic and Imaging Nursing https://www.arinursing.org/resources/practice-guidelines/	Practice Guidelines	Yes	Yes	PDF	Browsable repository of published clinical practice guidelines
Choosing Wisely® https://www.choosingwisely.org/clinician-lists/	Clinician Lists	Yes	Yes	Web links, PDF	Searchable, filterable repository of recommendations by medical/professional society
Clinical Pharmacogenetics Implementation Consortium https://cpicpgx.org/guidelines/	Guidelines	Yes	Yes	PDF, web links	Browsable repository of published clinical practice guidelines
Clinical Pharmacogenetics Implementation Consortium https://cpicpgx.org/genes-drugs/	Genes – Drugs Guidelines	Yes	Yes	CSV	Browsable repository of guidelines related to genes and drugs
Clinical Pharmacogenetics Implementation Consortium https://cpicpgx.org/alleles/	Alleles – Guidelines	Yes	Yes	CSV	Browsable repository of alleles discussed in guidelines and manuscripts
College of American Pathologists https://www.cap.org/protocols-and-guidelines/current-cap-guidelines	Clinical Guidelines	Yes	Yes	PDF	Browsable repository of published clinical practice guidelines

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
College of American Pathologists https://www.cap.org/protocols-and-guidelines/cancer-reporting-tools/cancer-protocol-templates	Cancer and Biomarker Reporting Protocols	Yes	Yes	PDF	Browsable repository of guidelines for collecting data elements for reporting cancer and for commonly ordered biomarkers
Congress of Neurological Surgeons https://www.cns.org/guidelines/browse-guidelines	Guidelines	Yes	Yes	PDF	Browsable repository of published clinical practice guidelines; some linked from other sites
Dataverse https://dataverse.harvard.edu/	Generalist Data Repository	Yes + Restricted Access	Yes	STATA, CSV, SPSS, etc.	Data repository for all disciplines that can be as open or restricted as the contributor defines, with permanent identifier and open metadata; includes medicine, health, and life sciences
diversitydatakids.org https://www.diversitydatakids.org/	Datasets	Yes	No	CSV; datasets available via API	Searchable and browsable repository of data related to childhood equity and opportunity
Dryad https://datadryad.org/stash/	Generalist Data Repository	Yes	Yes	FAIR Data Principles	Searchable, filterable generalist repository of reusable, open research data that includes health data
ECRI Institute https://www.ecri.org/topics/Pages/Topics.aspx https://www.ecri.org/solutions/ecri-guidelines-trust	Healthcare Repository/ECRI Guidelines Trust	Restricted Access (Subscription/Registration)	Yes	Web links, PDF	Searchable, browsable repository offering clinical evidence, guidelines, best practices for patient safety, and technology decision support
Figshare https://figshare.com/	Generalist Data Repository	Yes + Restricted Access	Yes	Variable	Generalist data repository offering alignment with technical and publishing principles for open research and offering API for automated research flows; access depends upon data contributor settings
GuidelineCentral https://www.guidelinecentral.com/summaries/	Guideline Summaries	Yes + Restricted Access (Subscription)	Yes	Web links, HTML	Viewable, searchable library of guidelines from societies and government sources, including USPSTF

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
Infectious Disease Society of America https://www.idsociety.org/practice-guideline/practice-guidelines/#/date_na_dt/DESC/0/+/	Clinical Practice Guidelines	Yes	Yes	GRADE	Searchable and filterable repository of clinical practice guidelines developed from systematic reviews of evidence and that use the GRADE process to develop recommendations
Michigan Quality Improvement Consortium http://www.mqic.org/guidelines.htm	MQIC Guidelines	Yes	Yes	Web links, PDF	Browsable repository of guidelines updated every 2 years
National Health Care for the Homeless Council https://nhchc.org/clinical-practice/adapted-clinical-guidelines/	Adapted Clinical Guidelines	Yes	Yes	PDF	Clinical guidelines adapted to challenges presented by homelessness
National Kidney Foundation https://www.kidney.org/professionals/guidelines	Guidelines	Yes	Yes	PDF	Browsable set of clinical guidelines also offered via mobile application
National Society of Genetic Counselors https://www.nsgc.org/page/practiceguidelines	Guidelines	Yes	Yes	PDF	Browsable repository of practice guidelines
Orphanet Orphadata http://www.orphadata.org/cgi-bin/index.php	Orphadata	Yes + Restricted Access (License Fee)	Yes	XML	Searchable repository of free and on-request datasets related to rare diseases and orphan drugs
PCORnet® https://pcornet.org	Network of PCOR research networks	Variable	Yes	Variable	Links to several PCOR networks (ADVANCE, CAPriCORN, etc.) offering access to PCOR data; data may adhere to the PCORnet common data model

Other Repositories/URL	Repository Name/Other Descriptive Information	Free/Open Access?	Timely (data from 2017 or later)?[120]	Identified Standards or Formats	Description
PROSPERO (National Institute for Health Research, UK) https://www.crd.york.ac.uk/prospero/#aboutpage	Systematic Reviews	Yes	Yes	PDF	International repository of systematic reviews in health and other domains, and where there is a health-related outcome
Society of Critical Care Medicine https://www.sccm.org/Research/Research/Discovery-Research-Network/Discovery-Resources/Data-Sets	Data Sets	No	Undetermined	Undetermined	Datasets are, at times, made available after publication of the data by study investigators
Society of Critical Care Medicine https://www.sccm.org/Research/Guidelines/Guidelines	Guidelines	Yes	Yes	Web links, PDF; mobile application	Browsable repository of clinical, administrative, and endorsed guidelines, grouped by year (2012–2020)
The Society for Healthcare Epidemiology of America	Guidelines and Expert Guidance	Yes + Restricted Access	Variable	Web links, PDF	Browsable repository of guidelines and guidance documents

Appendix C IT Standards

The environmental scan included review of existing and emerging health IT standards that could play a role in the CEDAR reference implementation. The CEDAR RI is intended to be developed using a FHIR-based API, but other types of standards beyond exchange standards may play an equally important role in current and future iterations of the CEDAR RI.

C.1 HL7 Standards

Health Level 7 standards provide a framework for the exchange, integration, sharing, and retrieval of electronic health information and address the interoperability component of the FAIR principles.[121] The HL7 FHIR standard describes data formats and elements for exchanging healthcare information electronically and is the basis for APIs included in the CEDAR RI.[122] Use of the FHIR standard aligns with the Department of Health and Human Services (HHS) "2020-2025 Federal Health IT Strategic Plan," which indicates it is the preferred standard for representing, exchanging, securing, and using clinical data for a patient to successfully advance health data interoperability.[123] Two of the FHIR standards reviewed support an API for EHRs, and the others describe data formats and elements used to represent knowledge artifacts.

C.1.1 SMART® Application (App) Launch Framework v1.0.0

The SMART® App Launch Framework connects third-party applications to EHR data, allowing applications to launch from within or without an EHR workflow.[124]

C.1.2 SMART Backend Services: Authorization Guide v1.0.0

The SMART Backend Services specification describes registration-time metadata required for a client to be pre-authorized and the runtime process by which the client acquires an access token that can be used to retrieve FHIR resources.[125]

C.1.3 InfoButton

The HL7 InfoButton standard was developed in 2010 to provide a standard set of metadata and a mechanism to search for and retrieve knowledge artifacts (e.g., patient education or provider reference materials) from repositories of varied technical capabilities.[126] The standard has been kept up to date and is implemented around the world.

As standards evolve and regulations require API-driven implementations, the InfoButton specification may be updated to be FHIR based. The Centers for Medicare & Medicaid Services

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121 HL7, Introduction to HL7 Standards, https://www.hl7.org/implement/standards/.

122 HL7, HL7 Standards – Section 1c: FHIR-Fast Health Interop Resources, https://www.hl7.org/implement/standards/product_section.cfm?section=12.

123 HHS Office of the National Coordinator for Health Information Technology, 2020-2025 Federal Health IT Strategic Plan, https://www.healthit.gov/topic/2020-2025-federal-health-it-strategic-plan.

124 http://www.hl7.org/fhir/smart-app-launch/.

125 http://build.fhir.org/ig/HL7/bulk-data-export/authorization/index.html.

126 https://www.hl7.org/implement/standards/product_brief.cfm?product_id=208.

has developed Blue Button 2.0, an implementation guide that constrains InfoButton and defines profiles on FHIR resources.

C.1.4 FHIR Clinical Reasoning Module

The FHIR Clinical Reasoning Module is an informative specification that describes the necessary FHIR resources to define components of a knowledge artifact (e.g., treatment recommendations), higher-level components (e.g., order set, care plan, quality measure, and questionnaire), and the structure to share the definitions between trading partners.[127] It references multiple FHIR IGs that address specific domains, one of which is clinical practice guidelines.[128]

C.1.5 Clinical Quality Language

Clinical Quality Language is a domain-specific language focused on clinical quality targeted at measure and decision support authors.[129] CQL defines the logic portion of knowledge artifacts such as clinical practice guidelines and decision support.

C.1.6 Clinical Guidelines

This FHIR IG supports the development of standards-based computable representations of the clinical practice guideline content.[130] A professional society may define a clinical practice guideline for breast cancer care. A user searching repositories for breast cancer evidence may discover a guideline of interest, and the repository returns a FHIR PlanDefinition resource containing the necessary diagnostic and treatment definitions.

C.1.7 CDS Hooks

CDS Hooks is a SMART on FHIR[131] implementation that describes how a third-party CDS system may integrate with an EHR.[132] The CDS system is notified when specific activities occur. The CDS system responds with information in the form of cards that may be displayed to an end user or otherwise incorporated into a workflow. A card may include text, actionable suggestions, or links to launch a SMART app.

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127 http://www.hl7.org/fhir/clinicalreasoning-module.html.

128 FHIR Clinical Guidelines Implementation Guide, http://build.fhir.org/ig/HL7/cqf-recommendations/.

129 https://cql.hl7.org/.

130 FHIR Clinical Guidelines Implementation Guide, http://build.fhir.org/ig/HL7/cqf-recommendations/.

131 https://smarthealthit.org/smart-on-fhir-api/.

132 https://cds-hooks.org/.

C.1.8 Miscellaneous FHIR Resources

FHIR defines infrastructure and workflow that may support repository implementations. These include:

- **Provenance.**[133] Used to track information about the context of the information in a resource, including creation, revision, review, approval. Provenance supports the *findable* component of FAIR Principles.
- **CapabilityStatement.**[134] FHIR servers are expected to provide a CapabilityStatement resource that describes solution capabilities. CapabilityStatement supports the *accessibility* component of FAIR Principles.
- **ResearchStudy.**[135] This resource describes essential data about a research study (e.g., clinical trial), including the purpose, objective, sponsor, investigator, therapy, and condition studied.

C.2 Emerging FHIR Standards

This subsection provides an overview of new or emerging FHIR standards:

- **Evidence-Based Medicine (EBM)-on-FHIR.** This emerging standard includes evidence definition resources, including Citation, which is used by CEDAR to manage metadata for repository products. It has become a priority because of the need to provide access to the most up-to-date, evidence-based knowledge regarding COVID-19 treatment.[136]
- **FAIRness for FHIR.** This project is sponsored by the HL7 Services Oriented Architecture Work Group.[137] The project scope is to develop a FHIR Implementation Guide (FHIR4FAIR) to determine how well FHIR satisfies the FAIRness of data via Maturity Indicators, as well as identify how well key components of FAIR data (persistent identifiers, metadata, provenance) align with FHIR resources.

C.3 Integrating the Healthcare Enterprise

Integrating the Healthcare Enterprise work groups create use-case-specific implementation profiles, often leveraging other interoperability standards.[138] One example of a relevant IHE standard is Computable Care Guidelines (CCG).[139] CCG references the IHE Dynamic Care Planning profile and several FHIR knowledge definition resources. It supports the expression of and sharing of healthcare guidelines in a grammar that can be ingested and understood by a software application.

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133 https://www.hl7.org/fhir/provenance.html.

134 https://www.hl7.org/fhir/capabilitystatement.html.

135 https://www.hl7.org/fhir/researchstudy.html.

136 https://confluence.hl7.org/display/CDS/EBMonFHIR.

137 https://jira.hl7.org/browse/PSS-1657; see also https://www.hl7.org/special/Committees/projman/searchableProjectIndex.cfm?action=edit&ProjectNumber=1651

138 https://www.ihe.net/.

139 https://wiki.ihe.net/index.php/Computable_Care_Guidelines.

C.4 Object Management Group

Object Management Group®[140] maintains the Business Process Model and Notation (BPMN) 2.0 standard, which describes a graphical notation to specify business processes in a Business Process Diagram.[141] BPMN artifacts may be translated into software process components (BPMN Interchange format). BPMN is an International Standards Organization/International Electrotechnical Commission standard.[142]

A second OMG standard, BPM Plus (BPM+), combines BPMN, Case Management Model and Notation, and the Decision Model and Notation specifications.[143] BPM+ enables the creation and sharing of Shareable Clinical Pathways that are platform independent, may be consumed and localized by an organization other than the author/publisher, provide technical rigor, and are understandable by business analysts and healthcare professionals.

C.5 Other Standards

Other standards of potential relevance to the CEDAR RI include Grading of Recommendations Assessment, Development, and Evaluation (GRADE) and Population, Intervention, Comparison, Outcome (PICO):

- **GRADE.** The GRADE system defines a quantitative framework to assess the quality of clinical evidence and strength of recommendations.[144] The GRADE score may be useful to PCOR stakeholders as they search for and evaluate repository artifacts. The GRADE system has been incorporated into various guideline evaluation tools such as AGREE Plus[145] and MAGICapp.[146]
- **PICO.** PICO defines a model for researchers to formulate an answerable question when performing a systematic review of clinical literature or knowledge artifacts.[147] Clearly defined population, intervention, comparison, and outcomes form the foundation of quality searches. When provided as metadata for repository artifacts, the four components support the *findable* component of the FAIR Principles.

C.5.1 Metadata Standards

Metadata standards define data to describe data. Some are general while others supplement general standards for specific scenarios. Metadata standards support the *findabl*e and *reusable* components of the FAIR Principles. Examples of relevant metadata standards include:

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140 https://www.omg.org/.

141 Business Process Model and Notation, version 2.0 (December 2010), https://www.omg.org/spec/BPMN/2.0/.

142 https://www.iec.ch/homepage.

143 https://www.omg.org/events/tn-19/special-events/BPM-Health-Workshop.htm.

144 GRADE Working Group, https://www.gradeworkinggroup.org/.

145 https://www.agreetrust.org/resource-centre/agree-plus/.

146 https://magicevidence.org/.

147 Davies, KS, Formulating the Evidence Based Practice Question: A Review of the Frameworks, Evidence Based Library and Information Practice (2011).

- **Metadata Component of FHIR Clinical Reasoning Module.** The FHIR Clinical Reasoning Module includes a metadata component with suggested terminology bindings to provide consistent metadata representation.
- **Dublin Core™.** Dublin Core is a joint U.S. National Information Standards Organization/American National Standards Institute (ANSI) standard Z39.85-2012.[148] The standard describes metadata elements for resource descriptions in a cross-disciplinary information environment. Domain-specific profiles have been created using Dublin Core as the base (e.g., the OpenAIRE Guidelines for Literature Repositories).
- **Common European Research Information Format (CERIF).** CERIF defines a set of metadata, extending Dublin Core, recommended by the European Union, to record information about research activity.[149] OpenAIRE has extended CERIF to allow research institutions to make their scholarly outputs visible through the OpenAIRE infrastructure.

Table C-1. Comprehensive Catalogue of Health IT Standards Assessed

Source	Supports	Name	Description
HL7 FHIR	Reference Implementation	SMART Application Launch Framework V1.0.0	Provides a reliable, secure authorization protocol for a variety of application architectures
HL7 FHIR	Reference Implementation	SMART Backend Services: Authorization Guide V1.0.0	Intended to be used by back-end services that autonomously (or semi-autonomously) need to access resources from FHIR servers that have pre-authorized defined scopes of access
HL7 FHIR	Reference Implementation	CDS Hooks	Describes the RESTful APIs and interactions to integrate CDS between CDS Clients and CDS Services
HL7 FHIR	Reference Implementation Resource	CapabilityStatement	FHIR server declaration of supported features/functions
HL7 FHIR	Knowledge Artifact	CARIN Consumer Directed Payer Data Exchange (CARIN IG for Blue Button®)	Explanation of Benefits (EOB)-focused
HL7 FHIR	Knowledge Artifact	EBMonFHIR	Emerging standard to represent evidence-based knowledge artifacts
HL7 FHIR	Knowledge Artifact	Fairness for FHIR	Emerging standard to provide guidance on how FHIR can be used to support FAIR health data implementation and assessment
HL7 FHIR	Knowledge Artifact	FHIR Clinical Guidelines	Computable representation of a clinical practice guideline

[148] https://dublincore.org/.

[149] https://www.eurocris.org/services/main-features-cerif.

Source	Supports	Name	Description
HL7 FHIR	Knowledge Artifact	FHIR-based context-aware knowledge retrieval (InfoButton on FHIR) Implementation Guide	Suspended FHIR project to replace the V3 normative specification
HL7 FHIR	Knowledge Artifact	FHIR Clinical Reasoning Module	Describes a process to define, share, and distribute knowledge artifacts, including quality measures, guidelines, decision support rules, order sets, and protocol definitions
HL7 FHIR	Knowledge Artifact Infrastructure Resources	Provenance ResearchStudy	Provenance provides metadata as well as life-cycle tracking for a resource ResearchStudy may be used to define a clinical trial; this resource is at a low maturity level.
HL7 V3 Specification	Knowledge Artifact	Context Aware Knowledge Retrieval (Info Button)	Standard mechanism for clinical information systems to request context-specific clinical knowledge from online resources
IHE	Knowledge Artifact	Computable Care Guidelines Profile	Leverages HL7 FHIR Clinical Guidelines
Centers for Medicare & Medicaid Services	Knowledge Artifact	Blue Button 2.0 Implementation Guide	Blue Button is the Centers for Medicare & Medicaid Services implementation of HL7 Context Aware Knowledge Retrieval (InfoButton)
OMG	Knowledge Artifact	BPMN and BPMN+	Enable sharing and development of Shareable Clinical Pathways
Research Data Alliance (RDA)	Knowledge Artifact	Health Data Implementation Guide – Reproducible Workflows in Healthcare	Framework to evaluate reproducibility in biomedical research
GRADE	Knowledge Artifact	Grading of Recommendations Assessment, Development and Evaluation	An approach created to synthesize and qualify evidence while developing a guideline—targeted to guideline developers
National Academy of Medicine	Knowledge Artifact	Trustworthiness Standard	Trustworthiness measure for guideline quality
Richardson et al.	Knowledge Artifact	PICO Framework for research questions	Note: Variations have been proposed over time
Dublin Core Metadata Initiative	Knowledge Artifact	Dublin Core	Metadata standard—not healthcare knowledge artifact specific
European Commission to euroCRIS (Current Research Information Systems)	Knowledge Artifact	Common European Research Information Format	Supplements Dublin Core for healthcare research

Appendix D Stakeholder Engagement and Collaboration

The environmental scan identified stakeholders associated with each of the AHRQ CEPI repositories to identify similarities in stakeholders between the different repositories and better understand the scope of each repository's reach and stakeholder community. The assessment will be used to strategize stakeholder outreach, engagement, and collaboration to inform CEDAR reference implementation development.

This appendix provides a high-level overview of the stakeholder types for the Effective Health Care (EHC) Program, the Systematic Review Data Repository™ (SRDR), the U.S. Preventive Service Task Force (USPSTF), CDS Connect, and the National Guideline Clearinghouse™ (NGC). Findings also include an initial assessment and review of stakeholders associated with the ACTS Initiative (AHRQ evidence-based Care Transformation Support), as that initiative is closely aligned with CEDAR and has done considerable work to engage and identify stakeholders.

D.1 EHC Program Stakeholders

The EHC Program engages a diverse range of stakeholders throughout the research process to ensure relevancy and transparency.[150] The EHC Program defines a "stakeholder" as a person or group with a vested interest in a particular clinical decision and the evidence that supports that decision.[151] EHC stakeholders can provide insights to CEDAR RI development related to the dissemination of evidence reports.

EHC Program stakeholders are involved throughout the process of designing, conducting, translating, disseminating, and implementing patient-centered outcomes research. Stakeholders nominate, prioritize, and refine research topics; provide scientific input and guidance; serve as peer reviewers; assist with translating research findings; and help disseminate and implement EHC products. EHC research reviews, original research reports, and research summaries are designed to help clinicians, consumers, and policymakers make better decisions about treatment.[152] The following stakeholder groups[153] are relevant to the EHC Program:

- Patients, caregivers, and patient advocacy organizations
- Clinicians and their professional associations
- Institutional healthcare providers (e.g., hospital systems and medical clinics)
- Government agencies

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150 Evidence-based Practice Center (EPC) Program Overview, https://www.ahrq.gov/research/findings/evidence-based-reports/overview/index.html. Stakeholders include: patients, caregivers, and patient advocacy organizations; clinicians and their professional associations; and government agencies.

151 Defining the Benefits of Stakeholder Engagement in Systematic Reviews, https://www.ncbi.nlm.nih.gov/books/NBK196176/

152 The Effective Health Care Program, https://www.ahrq.gov/cpi/about/otherwebsites/effectivehealthcare.ahrq.gov/index.html#:~:text=Other%20EHC%20Program%20stakeholders%20include,representatives%2C%20purchasers%2C%20and%20payers

153 The Effective Health Care Program, https://www.ahrq.gov/cpi/about/otherwebsites/effectivehealthcare.ahrq.gov/index.html#:~:text=Other%20EHC%20Program%20stakeholders%20include,representatives%2C%20purchasers%2C%20and%20payers

- Purchasers and payers, such as employers and public and private insurers
- Healthcare industry representatives
- Healthcare policymakers at the Federal, State, and local levels
- Healthcare researchers and research institutions

Critical components of the EHC Program are the Evidence-based Practice Centers (EPCs). EPCs engage stakeholders at several distinct points throughout the life cycle of evidence reports from topic refinement through report dissemination.[154] Stakeholder engagement efforts initially focused on defining opportunities and developing materials to involve stakeholders in systematic reviews. Over time, the basic mechanics of working with stakeholders have become a routine part of the systematic review process, allowing the program to begin to explore how to improve stakeholder engagement and make it more effective.

D.2 SRDR Platform Stakeholders

EPCs working within the EHC Program are instrumental in the development of evidence reports, systematic reviews, and other evidence reviews. The evidence tables for these reports are housed in the SRDR stewarded by the Brown University EPC.

SRDR is a data repository and resource for organizations and individuals seeking the evidence tables and information that underlie evidence reviews. SRDR includes a tool for abstraction to facilitate use of the data it contains. Access to these data facilitates transparency, cooperation, efficiency, and exploration of other areas of inquiry.[155]

Although the targeted primary users of SRDR are systematic review developers, including AHRQ-designated EPCs, SRDR also allows users of systematic reviews, such as guideline developers, policymakers, patients, and the public, to access study data that might be relevant to their decision-making processes.[156] In the SRDR 2015 Annual Report, the authors stated that the goal of SRDR is to "facilitate the efficient generation and update of evidence reviews, thus speeding up and improving policymaking with regards to healthcare."[157] Subsequent annual reports include more specific information about users who have registered for education sessions to learn how to contribute data to SRDR+ and are informative as to the specific organizations using the repository.[158] SRDR stakeholders may provide insights to CEDAR RI on the findability and other FAIR aspects of clinical and other scientific research datasets.

D.3 USPSTF Stakeholders

The USPSTF consists of experts in the fields of preventive medicine and primary care, including internal medicine, family medicine, pediatrics, behavioral health, obstetrics/gynecology, and

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154 Stakeholders conducting research at the EPCs are medical doctors, pharmacy doctors, psychologists, physical therapists, and other medical specialists. They may also be researchers trained in different types of health research, such as epidemiology, health services research, and organizational change.

155 About the Systematic Review Data Repository Plus (SRDR+), https://srdrplus.ahrq.gov/about.

156 About the Systematic Review Data Repository, https://srdr.ahrq.gov/about

157 Brown EPC, Systematic Review Data Repository (SRDR) Annual Report, December 2014 to November 2015, https://s3.amazonaws.com/srdr/SRDR+2015+Annual+Report.pdf.

158 Brown EPC, Systematic Review Data Repository (SRDR) and SRDR+ Annual Report, January 2020 through December 2020, https://srdr.s3.amazonaws.com/SRDR+Annual+Report/SRDR+2021_Annual+Report.pdf.

nursing. The USPSTF leverages relationships with partner organizations to disseminate and implement the guidelines it offers on its website.[159] The main stakeholders for the USPSTF are primary care clinicians, but other stakeholders are also engaged. Partner organization representatives contribute their expertise, disseminate the work of the USPSTF to their members and constituents, and implement recommendations.[160]

Partner organizations include Federal agencies that are stakeholders in the process (Federal Liaisons) and representatives of primary care clinicians, consumers, and other stakeholders involved in the delivery of primary care (Dissemination and Implementation Partners).

Partners and the public are invited to review draft research plans, evidence reviews, and recommendation statements. Partner organizations may provide additional peer review by content experts in their organizations. This is in addition to the peer review that is obtained from experts who are not involved in the Task Force process, and the peer review provided by journals. USPSTF stakeholders may inform the CEDAR RI on topics of guideline dissemination and public engagement.

USPSTF stakeholders include:

- American Association of Retired Persons (AARP)
- America's Health Insurance Plans (AHIP)
- American Academy of Family Physicians (AAFP)
- American Academy of Nurse Practitioners (AANP)
- American Academy of Pediatrics (AAP)
- American Academy of Physician Assistants (AAPA)
- American College of Obstetricians and Gynecologists (ACOG)
- American College of Physicians (ACP)
- American College of Preventive Medicine (ACPM)
- American Medical Association (AMA)
- American Osteopathic Association (AOA)
- American Psychological Association (APA)
- Canadian Task Force on Preventive Health Care
- Community Preventive Services Task Force
- Consumers Union
- National Association of Pediatric Nurse Practitioners (NAPNAP)

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[159] Partner organizations include Federal agencies that are stakeholders in the process (Federal Liaisons) and Dissemination and Implementation Partners that represent primary care clinicians, consumers, and other stakeholders involved in the delivery of primary care.

[160] Dissemination and Implementation Partners currently include AARP, AHIP, AAFP, AANP, AAP, AAPA, ACOG, ACP, ACPM, AMA, AOA, APA, Canadian Task Force on Preventive Health Care, Community Preventive Services Task Force, Consumers Union, NAPNAP, National Business Group on Health, NCQA, and PCORI.

- National Business Group on Health
- National Committee for Quality Assurance (NCQA)
- Patient-Centered Outcomes Research Institute® (PCORI)

D.4 CDS Connect Stakeholders

CDS Connect is both a platform and a community of contributors and users. Central to CDS sharing is the CDS Connect Repository (the "Repository") of CDS knowledge artifacts. Through the Repository, CDS contributors and CDS consumers have access to CDS artifacts. Organizations can leverage advanced technical resources and tools posted within artifacts to aid in the implementation of the CDS logic. CDS Connect offers interoperable tools and resources, and its content is expected to adhere to clinical and technical standards.[161]

CDS Connect engages with stakeholders for both creation and utilization purposes.[162] CDS Connect maintains a stakeholder work group that advises it on all aspects of work, including the identification and prioritization of key features and capabilities for CDS Connect systems and tools.[163] CDS Connect stakeholders can inform the CEDAR RI on matters such as variety across artifacts and clinical decision support tool access through repositories.

Work group meetings are attended by a broad array of CDS stakeholders, including subject matter experts from across government, industry, academia, clinical settings, and nonprofits. Work group members provide input on topics such as artifact development, prioritization of prototype tool development and features, and enhancements to existing tools.

CDS Connect engages various stakeholder types including:

- Federal agencies
- Academic institutions
- Research organizations
- Healthcare systems
- Preventive health subject matter experts
- Primary care health innovators and health knowledge efforts
- Interoperability and terminology teams
- EHR vendor organizations
- Technology companies

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[161] CDS Connect Contract Year 3 Final Report, https://cds.ahrq.gov/sites/default/files/AHRQ_Final_Report_2019.pdf.

[162] CDS Connect stakeholders include Federal agencies, academic institutions, research organizations, healthcare systems, preventive health subject-matter experts, primary care health innovators, health knowledge efforts such as MCBK, interoperability and terminology initiatives, EHR vendor organizations, technology companies, health center-controlled networks, and patient advocates.

[163] CDS Connect Work Group, https://cds.ahrq.gov/cdsconnect.

- Health center-controlled networks
- Patient advocates

D.5 National Guideline Clearinghouse

The NGC provided access to evidence-based clinical practice guidelines in a variety of forms: the guidelines themselves, guideline summaries/structured abstracts, guideline syntheses, and the generation of comparison across guidelines specified by users. Entities who identified as NGC stakeholders can provide insights to CEDAR on questions of copyright and other intellectual property, as well as dissemination of guidelines. In general, end users of the NGC repository were:[164]

- Health professionals, systems, and organizations
- Health plans and employer benefits managers
- Medical specialty and professional societies
- Researchers and medical librarians
- Health policymakers (including from Federal, State, and local governments)
- Health profession educators and students
- Web developers

D.6 ACTS Stakeholders

In 2019, the ACTS Stakeholder Community was founded to create a shared future vision for health IT-enabled, evidence-informed care delivery that fully leverages AHRQ and other resources. The Stakeholder Community numbers 268 members as of January 2021.[165]

There are 10 stakeholder types that represent the individuals participating in the ACTS Stakeholder Community as shown in Table D-1. Some organizations have more than one individual participating in the ACTS volunteer Stakeholder Community.

Table D-1. ACTS Initiative Stakeholder Types

Stakeholder Type	Current Number of Organizational Participants
Care Delivery Organizations	35
Health Information Technology (HIT)/CDS Suppliers	30
Informatics/Researchers	15
Patient Advocates	3
Payers	3
Quality Organizations/Consultants	25
Specialty Societies	8

[164] Repository steward discussion and communications, September 2020 through February 2021.

[165] https://digital.ahrq.gov/acts/stakeholder-community. The stakeholder community list was last updated in October 2020.

Stakeholder Type	Current Number of Organizational Participants
AHRQ	5
Other Government Agencies	9
Other	13

One of ACTS' main objectives is to build a stakeholder-driven Roadmap to ensure that the AHRQ Digital Knowledge Platform and knowledge ecosystem support AHRQ's mission and priorities, enabling learning health systems to achieve the quadruple aim.[166] The ACTS Stakeholder Community and Workgroups are working to produce the Roadmap, while also focusing on work in areas such as the Evidence/Knowledge/Tools Marketplace, Infrastructure/Standards, and Concept Demonstration.[167] The ACTS Initiative can inform the CEDAR RI through understanding stakeholder input on ACTS goals and the overall learning health system landscape.

[166] https://www.annfammed.org/content/12/6/573.full. The Quadruple Aim is better outcomes, improved clinician experience, lower costs, and improved quality. https://digital.ahrq.gov/acts/quadruple-aim.

[167] https://digital.ahrq.gov/sites/default/files/docs/page/amia-ahrq-s43-panel-slides-2020.pdf.

Appendix E Repository Metadata Structure

This appendix crosswalks the metadata stored with each product for each of the repositories studied during the environmental scan. This metadata can be used in search queries to filter results.

E.1 Crosswalks of Metadata and Other Characteristics Between AHRQ CEPI PCOR Repositories

Key:

Response	Description
Y	**Yes** (100 percent match)
P	Partial match (actual data match)
Blank	No = No match

Table E-1. Crosswalk by Topic

Topic	EPC	EHC	NGC	USPSTF	CDS Connect
Anesthesiology	No	No	**Yes**	No	No
Blood Disorders	**Yes**	P (Blood, Heart, and Circulation)	P (Hematology)	No	No
Cancer	**Yes**	**Yes**	P (Oncology; Radiation Oncology)	**Yes**	No
Chiropractic	No	No	**Yes**	No	No
Complementary and Alternative Care	**Yes**	**Yes**	No	No	No
Critical Care	No	No	**Yes**	No	No
Dentistry	No	No	**Yes**	No	No
Diabetes Mellitus	P (Endocrine Conditions)	**Yes**	P (Endocrine Conditions)	No	**Yes**
Drug Therapy	No	**Yes**	P (Pharmacology)	No	No
Ear, Nose, Throat, and Oral Conditions	**Yes**	P (Ear, Nose, and Throat; Mouth and Teeth)	P (Otolaryngology)	P (Vision and Hearing Disorders)	No

Topic	EPC	EHC	NGC	USPSTF	CDS Connect
Emergency Medicine	No	No	**Yes**	No	No
Endocrine Conditions	**Yes**	**Yes**	**Yes**	P (Metabolic, Nutritional, and Endocrine Conditions)	No
Eye Disorders	**Yes**	P (Eyes and Vision)	P (Ophthalmology; Optometry)	P (Vision and Hearing Disorders)	P (Eye Diseases)
Family Practice	No	No	**Yes**	No	No
Fitness and Exercise	No	**Yes**	No	No	No
Food and Nutrition	No	**Yes**	**Yes**	P (Metabolic, Nutritional, and Endocrine Conditions)	No
Gastrointestinal Disorders	**Yes**	P (Digestive System)	P (Gastroenterology; Colon and Rectal Surgery)	No	P (Digestive System Diseases)
Genetic Conditions	**Yes**	P (Genetics/Birth Defects)	P (Medical Genetics)	No	No
Health Information Technology	**Yes**	No	No	No	No
Heart and Vascular Disease	**Yes**	P (Blood, Heart, and Circulation)	P (Cardiology)	P (Cardiovascular Disorders)	P (Cardiovascular System)
Health System	No	**Yes**	No	No	No
Immune System	No	**Yes**	P (Allergy and Immunology)	No	**Yes**
Infectious Diseases	**Yes**	P (Infections)	**Yes**	**Yes**	P (Bacterial Infections and Mycoses)
Injury Prevention	No	No	No	**Yes**	No
Internal Medicine	No	No	**Yes**	No	No
Kidney and Urological Conditions	**Yes**	**Yes**	P (Nephrology; Urology)	No	No

Topic	EPC	EHC	NGC	USPSTF	CDS Connect
Laboratory Testing	**Yes**	P (Diagnostic Tests)	P (Pathology)	No	No
Lung Conditions	**Yes**	P (Lungs and Breathing)	P (Pulmonary Medicine)	No	P (Respiratory Tract Diseases)
Male Reproductive System	No	**Yes**	No	No	No
Men	No	**Yes**	No	P (sex=Male)	No
Menopausal Hormone Therapy	Yes	No	No	No	No
Mental Health Conditions and Substance Abuse	**Yes**	P (Mental Health and Behavior; Substance Abuse Problems)	P (Psychiatry; Psychology)	**Yes**	P (Psychiatry and Psychology)
Metabolic Problems	No	**Yes**	No	P (Metabolic, Nutritional, and Endocrine Conditions)	P (Nutritional and Metabolic Diseases, Chemically Induced Disorders)
Methodology	**Yes**	No	No	No	No
Miscellaneous	No	No	No	**Yes**	No
Musculoskeletal Disorders	**Yes**	P (Bones, Joints, and Muscles)	No	**Yes**	**Yes**
Neoplasm	No	No	No	No	**Yes**
Nerve and Brain Conditions	**Yes**	**Yes**	P (Neurology; Neurological Surgery)	No	P (Trauma, Nervous System)
Nuclear Medicine	No	No	P (Nuclear Medicine; Radiation Oncology; Radiology)	No	No
Nursing	No	No	Yes	No	No
Obesity	**Yes**	No	No	No	**Yes**
Obstetric and Gynecologic Conditions	**Yes**	P (Female Reproductive System)	No	**Yes**	No

Topic	EPC	EHC	NGC	USPSTF	CDS Connect
Older Adults	**Yes**	P (Seniors)	P (Geriatrics)	P (Age Group = Senior)	No
Ovarian Cancer	**Yes**	No	No	No	No
Pediatric Conditions	**Yes**	P (Children and Teenagers)	**Yes**	P (Age Group = Pediatric, Adolescent)	No
Perinatal Care	No	No	No	**Yes**	No
Personal Health Issues	No	**Yes**	No	No	No
Podiatry	No	No	**Yes**	No	No
Poisoning, Toxicology, Environmental Health	No	**Yes**	No	No	No
Population Groups	No	**Yes**	No	No	No
Pregnancy and Reproduction	No	**Yes**	P (Obstetrics and Gynecology)	P (Obstetrics and Gynecology)	No
Public Health Preparedness	**Yes**	No	No	No	P (Public Health)
Quality Improvement and Patient Safety	**Yes**	P (Safety Issues)	No	No	No
Rheumatology	No	No	**Yes**	No	No
Sexual Health Issues	No	**Yes**	No	No	No
Skin Conditions	**Yes**	P (Skin, Hair, and Nails)	P (Dermatology)	No	P (Skin and Connective Tissue Diseases)
Social/Family Issues	No	**Yes**	No	No	No
Sleep Medicine	No	No	**Yes**	No	No
Speech-Language Pathology	No	No	**Yes**	No	No
Sports Medicine	No	No	**Yes**	No	No
Surgery and Rehabilitation	No	**Yes**	P (Orthopedic Surgery; Plastic Surgery; Thoracic Surgery; Surgery; Physical Medicine and Rehabilitation)	No	P (Rehabilitation)

Topic	EPC	EHC	NGC	USPSTF	CDS Connect
Symptoms	No	**Yes**	No	No	No
Tobacco Usage	No	No	No	**Yes**	No
Transplantation and Donation	No	**Yes**	No	No	No
Violence and Trauma	**Yes**	P (Injuries and Wounds)	No	No	P (Wound and Injuries)
Wellness and Lifestyle	No	**Yes**	P (Preventive Medicine)	No	No
Women	**Yes**	**Yes**	No	P (Sex = Female)	No

Table E-2. Crosswalk by Report Type

Report Type	EPC	EHC	NGC	USPSTF	CDS Connect
Abstract	No	**Yes**	No	No	No
Brochure	No	**Yes**	No	No	No
Clinician Summary	No	**Yes**	No	No	No
Comparative Effectiveness Reviews	**Yes**	No	No	No	No
Consumer Summary	No	**Yes**	No	No	No
Decision Aid	No	**Yes**	No	P (Recommendation)	No
Disposition of Comments Report	No	**Yes**	No	No	No
Evidence Reports	**Yes**	No	No	No	No
Executive Summary	No	**Yes**	No	No	No
Horizon Scan Status Update	No	**Yes**	No	No	No
Key Questions	No	**Yes**	No	No	No
Methods Guide – Chapter	No	**Yes**	No	No	No
Overview	No	**Yes**	No	No	No
Policymaker Summary	No	**Yes**	No	No	No

Report Type	EPC	EHC	NGC	USPSTF	CDS Connect
Potential High Impact Report	No	**Yes**	No	No	No
Presentation	No	**Yes**	No	No	No
Rapid Evidence Product	**Yes**	**Yes**	No	No	No
Research Protocol	No	**Yes**	No	No	No
Research Report	No	**Yes**	No	No	No
Series Overview	No	**Yes**	No	No	No
Systematic Review	No	**Yes**	No	No	No
Technical Brief	**Yes**	**Yes**	No	No	No
Technology Assessment Program Reports	**Yes**	No	No	No	No
Tools	No	No	No	**Yes**	No
U.S. Preventive Services Task Force Evidence Syntheses	**Yes**	No	No	No	No
White Paper	**Yes**	**Yes**	No	No	No

Table E-3. Crosswalk by Status and Year

Status	EPC	EHC	NGC	USPSTF	CDS Connect
Archived	No	**Yes**	No	No	P (Same as Retired)
Final	No	**Yes**	No	**Yes**	P (Same as Active)
Draft	No	P (Same as in progress?)	No	No	**Yes**
In Progress	P (Same as draft?)	No	No	P (Maybe)	No
Year of Publication	**Yes**	No	**Yes**	**Yes**	**Yes**

Table E-4. Crosswalk by Audience

Audience	EPC	EHC	NGC	USPSTF	CDS Connect
Advanced Practice Nurses	No	No	**Yes**	No	No
Allied Health Personnel	No	No	**Yes**	No	No
Chiropractors	No	No	**Yes**	No	No
Clinical Laboratory Personnel	No	No	**Yes**	No	No
Consumers	No	**Yes**	No	No	No
Dentists	No	No	**Yes**	No	No
Dietitians	No	No	**Yes**	No	No
Emergency Medical Technicians/Paramedics	No	No	**Yes**	No	No
Healthcare Providers	No	No	**Yes**	No	No
Health Plans	No	No	**Yes**	No	No
Hospitals	No	No	**Yes**	No	No
Managed Care Organizations	No	No	**Yes**	No	No
Nurses	No	No	**Yes**	No	No
Occupational Therapists	No	No	**Yes**	No	No
Optometrists	No	No	**Yes**	No	No
Other	No	No	**Yes**	No	No
Patients	No	No	**Yes**	No	No
Payer	No	No	No	No	No
Pharmacists	No	No	**Yes**	No	No
Physical Therapists	No	No	**Yes**	No	No
Physician Assistants	No	No	**Yes**	No	No
Physicians	No	No	**Yes**	No	No
Podiatrists	No	No	**Yes**	No	No
Professionals	No	**Yes**	No	No	No

Audience	EPC	EHC	NGC	USPSTF	CDS Connect
Psychologists/Non-physician Behavioral Health Clinicians	No	No	**Yes**	No	No
Public Health Departments	No	No	**Yes**	No	No
Quality Improvement Organization	No	No	No	No	No
Research Institution	No	No	No	No	No
Respiratory Care Practitioners	No	No	**Yes**	No	No
Social Workers	No	No	**Yes**	No	No
Speech-Language Pathologists	No	No	**Yes**	No	No
Students	No	No	**Yes**	No	No
Substance Use Disorders Treatment Providers	No	No	**Yes**	No	No
Tools and Software	No	**Yes**	No	No	No
Utilization Management	No	No	**Yes**	No	No

Table E-5. Crosswalk by Method

Method	EPC	EHC	NGC	USPSTF	CDS Connect
Original Methods Research: Systematic Reviews	No	**Yes**	No	No	No
Guidance on Methods for Systematic Reviews	No	**Yes**	No	No	No
Original Methods Research: Observational Studies	No	**Yes**	No	No	No
Original Methods Research: Communications/Decisions	No	**Yes**	No	No	No
Guidance on Methods for Registries	No	**Yes**	No	No	No
Guidance on Methods for Observational Research	No	**Yes**	No	No	No
Original Methods Research: Experimental Trials	No	**Yes**	No	No	No

Table E-6. Crosswalk by Authoring Institution

Authoring Institution	EPC	EHC	NGC	USPSTF	CDS Connect
AHRQ Grant	**Yes**	**Yes**	No	No	No
American Institutes of Research	No	**Yes**	No	No	No
Baylor College of Medicine	No	**Yes**	No	No	No
Blue Cross and Blue Shield Association, Technology Evaluation Center (TEC)	**Yes**	**Yes**	No	No	No
Brigham and Women's Hospital	No	**Yes**	No	No	No
Brown University	**Yes**	**Yes**	No	No	No
Center for Medical Technology Policy	No	**Yes**	No	No	No
CERT	No	No	No	No	No
CISNET	**Yes**	No	No	No	No
Community Forum	No	No	No	No	No
DEcIDE	No	No	No	No	No
Duke University	**Yes**	**Yes**	No	No	No
Duke University Medical Center	No	**Yes**	No	No	No
ECRI Institute	**Yes**	**Yes**	No	No	No
Eisenberg Center	No	No	No	No	No
EPC	No	No	No	No	No
HMO Research Network	No	**Yes**	No	No	No
Johns Hopkins University	**Yes**	**Yes**	No	No	No
Kaiser Permanente Research Affiliates	**Yes**	**Yes**	No	No	No
L&M Policy Research, LLC	No	**Yes**	No	No	No
Mayo Clinic Evidence-based Practice Center	**Yes**	**Yes**	No	No	No
McMaster University	**Yes**	**Yes**	No	No	No
MetaWorks Inc	**Yes**	No	No	No	No
Minnesota Evidence-based Practice Center	**Yes**	**Yes**	No	No	No

Authoring Institution	EPC	EHC	NGC	USPSTF	CDS Connect
No Agency	No	**Yes**	No	No	No
Oregon Health & Science University	No	**Yes**	No	No	No
Outcome Sciences	No	**Yes**	No	No	No
Pacific Northwest	**Yes**	**Yes**	No	No	No
RTI International	No	**Yes**	No	No	No
RTI International – University of North Carolina at Chapel Hill	**Yes**	**Yes**	No	No	No
Scientific Resource Center	**Yes**	**Yes**	No	No	No
Southern California Evidence-based Practice Center – RAND	**Yes**	**Yes**	No	No	No
SRC	No	No	No	No	No
Stanford University, Stanford, and University of California	**Yes**	**Yes**	No	No	No
Tufts University – New England Medical Center	**Yes**	**Yes**	No	No	No
University of Alberta	**Yes**	**Yes**	No	No	No
University of Colorado at Denver and Health Sciences Center	No	**Yes**	No	No	No
University of Connecticut	**Yes**	**Yes**	No	No	No
University of Illinois at Chicago	No	**Yes**	No	No	No
University of Minnesota School of Public Health	No	**Yes**	No	No	No
University of North Carolina at Chapel Hill	No	**Yes**	No	No	No
University of Ottawa	**Yes**	**Yes**	No	No	No
University of Pennsylvania School of Medicine	No	**Yes**	No	No	No
University of Texas Health Sciences Center	**Yes**	No	No	No	No
USPSTF	No	No	No	**Yes**	No
Vanderbilt University Medical Center	**Yes**	**Yes**	No	No	No

Appendix F Acronyms

Term	Definition
AAFP	American Academy of Family Physicians
AANN	American Association of Neuroscience Nurses
AANEM	American Association of Neuromuscular and Electrodiagnostic Medicine
AANP	American Academy of Nurse Practitioners
AAP	American Academy of Pediatrics
AAPA	American Academy of Physician Assistants
AARC	American Association for Respiratory Care
AARP	American Association of Retired Persons
ACA	Patient Protection and Affordable Care Act of 2010
ACC	American College of Cardiology
ACG	American College of Gastroenterology
ACNS	American Clinical Neurophysiology Society
ACOG	American College of Obstetricians and Gynecologists
ACP	American College of Physicians
ACPM	American College of Preventive Medicine
ACR	American College of Rheumatology
ACTS	AHRQ evidence-based Care Transformation Support
AGS	American Geriatrics Society
AHIP	America's Health Insurance Plans
AHRQ	Agency for Healthcare Research and Quality
AMA	American Medical Association
ANSI	American National Standards Institute
AOA	American Osteopathic Association
APA	American Psychological Association
API	Application Programming Interface
AWS	Amazon Web Services
BPM+	Business Process Model Plus
BPMN	Business Process Model Notation
CCG	Computable Care Guidelines

Term	Definition
CDC	Centers for Disease Control and Prevention
CDS	Clinical Decision Support
CEDAR	CEPI Evidence Discovery And Retrieval
CEPI	Center for Evidence and Practice Improvement
CERIF	Common European Research Information Format
CERTS	Centers for Education and Research on Therapeutics
CMS	Content Management System
CQL	Clinical Quality Language
CSS	Cascading Style Sheets
CSV	Comma-Separated Value
DB	Database
EBM	Evidence-based Medicine
EHC	Effective Health Care
EHR	Electronic Health Record
ELM	Expression Logical Model
EOB	Explanation of Benefits
EPC	Evidence-based Practice Center
FAIR	Findable, Accessible, Interoperable, and Reusable
FAQ	Frequently Asked Question
FDA	Food and Drug Administration
FFRDC	Federally Funded Research and Development Center
FHIR®	Fast Healthcare Interoperability Resource
GI	Gastrointestinal
GRADE	Grading of Recommendations Assessment, Development, and Evaluation
HHS	Department of Health and Human Services
HL7®	Health Level 7®
HRSA	Health Resources & Services Administration
HTML	Hypertext Markup Language
HTTPS	Hypertext Transfer Protocol
IG	Implementation Guide
IHE	Integrating the Health Enterprise

Term	Definition
IT	Information Technology
JSON	JavaScript Object Notation
LOINC	Logical Observation Identifiers, Names and Codes
MCBK	Mobilizing Computable Biomedical Knowledge
MeSH®	Medical Subject Headings
MRI	Magnetic Resonance Imaging
NAPNAP	National Association of Pediatric Nurse Associates and Practitioners
NCQA	National Committee for Quality Assurance
NGC	National Guideline Clearinghouse™
NIAID	NIH National Institute of Allergy and Infectious Disease
NIH	National Institutes of Health
OMG	Object Management Group
PCOR	Patient-Centered Outcomes Research
PCORI®	Patient-Centered Outcomes Research Institute®
PET	Positron Emission Tomography
PICO	Population, Intervention, Comparison, Outcome
RDA	Research Data Alliance
REST	Representational State Transfer
RI	Reference Implementation
RxNORM	Standardized nomenclature for clinical drugs (by National Library of Medicine)
SAMHSA	Substance Abuse and Mental Health Services Administration
SNOMED-CT	Systematised Nomenclature of Medicine-Clinical Terms
SRC	Scientific Resource Center
SRDR	Systematic Review Data Repository™
SRDR+	Systematic Review Data Repository Plus
UMLS®	Unified Medical Language System®
URL	Uniform Resource Locator
USPSTF	United States Preventive Service Task Force
VA	Department of Veterans Affairs

Term	Definition
WMO	World Meteorological Organization
XML	Extensible Markup Language