Public Health Data Standardization - Deep Dive on USCDI+ and the Helios HL7® FHIR® Accelerator

ONC Tech Forum, September 9th 2022
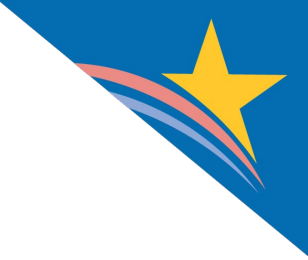
USDS/CDC Engagement

Using Data for Public Health Response

Lessons learned during the USDS engagement with CDC

U.S. DIGITAL SERVICE // September 2022

Public Health Data Exchange

Moving data between Healthcare, Public Health, and the CDC

CURRENT CHALLENGES WITH DATA EXCHANGE & DATA SYSTEMS

1 Public Health systems are not response ready, and in general are outdated

2 Onboarding new reporters is cumbersome, slow, and resource-intensive

3 The standards are not sufficient, leading to variability

4 Developing and maintaining customized systems and data formats is expensive

5 Public health is not well integrated with the healthcare delivery system

Public Health systems are not response ready, and in general are outdated

"Our epidemiologists waste 80% of their time cleaning data and can't do useful analysis. The end goal of all this infrastructure is to free up that 80% of their time to do actual public health work ."
–Los Angeles County

Onboarding new reporters is cumbersome, slow, and resource-intensive

When receiving data from health care and other data providers, Virginia spent substantial time and effort transforming the structure and semantics of the incoming data in order to ingest it into their systems.

With Promoting Interoperability requirements, lots of reporters will need to be onboarded quickly, across the country.

The standards are not sufficient, leading to variability

"The diversity of standards among and between each data element makes it so you can't easily compare data or derive analysis."
–California

Developing and maintaining customized systems and data formats is expensive

Bespoke processes and system customizations are resource-heavy and burdensome. When staff leave positions, knowledge is often lost with them.

Public health is not well integrated with the healthcare delivery system

"In 2018 and 2019, half of all hospitals reported a lack of capacity to electronically exchange information with public health agencies...about one in five hospitals reported issues exchanging information due to differing vocabulary standards."
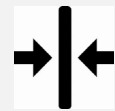–ONC Data Brief No. 56

ONC CDC Joint Priorities

Specific, Significant Shifts Are Occurring Which Can Benefit Public Health

Current State: High Processing Burden

ALIGNMENT WITHIN AND BEYOND PUBLIC HEALTH

Emerging State: Greater Connectivity & Flexibility

USCDI   HL7® FHIR   TEFCA
The Office of the National Coordinator for Health Information Technology

DATA USE AGREEMENTS NEGOTIATED ONE AT A TIME

COMMON AGREEMENTS & RULES OF THE ROAD ARE PRE-NEGOTIATED IN ADVANCE

DATA SENT MULTIPLE TIMES, IN MULTIPLE FORMATS TO MULTIPLE ENDPOINTS

STANDARDIZED DATA SENT & RECEIVED ONCE TO FILL MULTIPLE USERS' NEEDS

PH INFORMATION SYSTEMS LACK CONSISTENCY AND COMMON FUNCTIONALITIES

PH INFORMATION SYSTEMS ARE CONSISTENT ACROSS STLTS & CDC PROGRAMS

Value of USCDI, FHIR, & TEFCA

DMI
@ CDC

US Core Data for Interoperability (USCDI)

Create a Core Set of Standardized Data Elements for Health

Common core of standardized data to support treatment, payment, healthcare operations, requests from patients, post-market surveillance, research, public health, and other authorized uses.

https://www.healthit.gov/topic/interoperability/uscdi-plus
https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi

Value of USCDI and USCDI+ to Public Health

|	
Align	**Ensure data harmonization efforts are aligned and tightly coordinated to prevent redundancy, duplication of effort or misalignment of needs**
Sustain	**Build a foundation for standardizing data that is flexible, extensible and scalable—and can be sustained over time**
Adapt	**Develop expedited processes for setting priorities, developing consensus, and rolling out new capabilities as needs change**

Fast Healthcare Interoperability Resources (FHIR)

Access and Share Health Information Seamlessly

Set of best practices and open standards being developed and adopted by a global community to make data sharing more flexible and effective.

https://www.cdc.gov/surveillance/pdfs/20_319521-D_DataMod-Initiative_901420.pdf

Value of FHIR to Public Health

Inform	**Access detailed and actionable data, including data from clinical notes, that aren't easily available now**
Connect	**Work alongside partners from across healthcare, government, and the private sector to ensure public health gets the attention it needs and deserves as IT updates roll out nationwide**
Modernize	**Upgrade core data systems and capabilities so fast, accurate, and complete data get to all levels of public health smoothly and seamlessly**
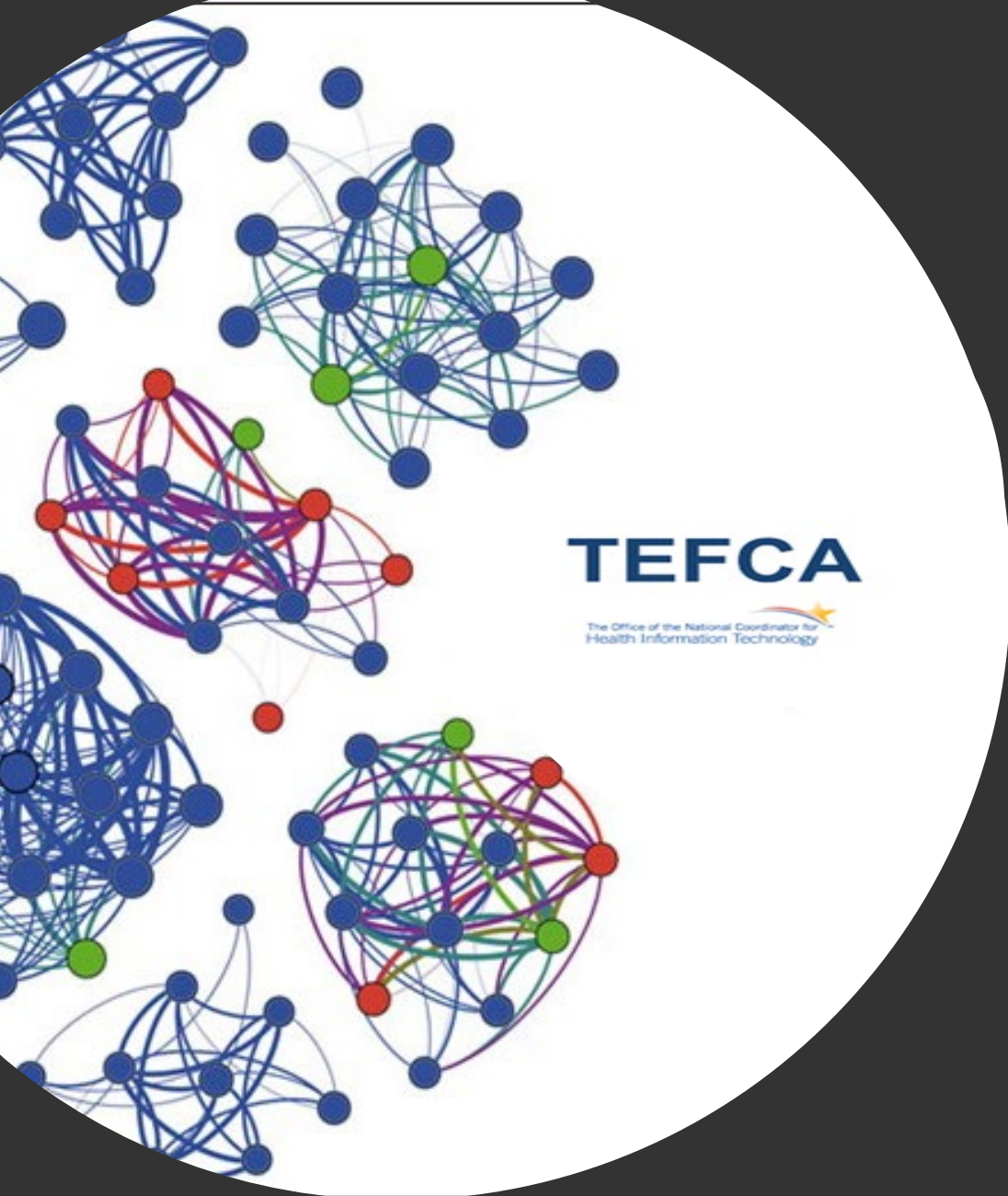
Trusted Exchange Framework and Common Agreement (TEFCA)

Pre-Negotiate Agreements to Simplify Data Exchange Nationwide

Common baseline of legal and technical requirements for secure and efficient data sharing within and across health information networks.

https://rce.sequoiaproject.org/benefits-for-state-governments-and-pubic-health/

Value of TEFCA to Public Health

Broaden	Broaden information available to public health
Simplify	Simplify processes for onboarding partners, filtering out what's relevant, and exchanging data
Strengthen	Strengthen privacy and security protections

Helios FHIR Accelerator

The Helios FHIR Accelerator for Public Health

ONC Tech Forum
September 9, 2022

HELIOS

What can be done to accelerate public health readiness to act on the data and use the data meaningfully?

What can we do to ensure that our efforts to influence healthcare partners are strategic and aligned?

How can we leverage policies and approaches to interoperability that have momentum and buy-in beyond public health?

HELIOS FHIR Accelerator

Helping public health to align with and benefit from the widespread standardization and transformation that is happening around digital health data

01 Multi-Sector Alliance

Diverse teams—across public health, healthcare, philanthropic organizations, and the private sector—work together to tackle longstanding challenges and explore new opportunities to advance interoperability.

02 Align Efforts

Align with and address known gaps in the FHIR standard to help promote more flexible and effective data exchanges with healthcare, the public, and other sectors beyond public health.

03 Focus on Impact

Prioritize a small set of use cases that complement what exists today and make it easier for public health officials to act swiftly, share insights effectively, and have a greater impact in their communities.

HELIOS

Value of FHIR to Public Health

Inform	Access detailed and actionable data, including data from clinical notes, that aren't easily available now
Connect	Work alongside partners from across healthcare, government, and the private sector to ensure public health gets the attention it needs and deserves as HIT updates roll out nationwide
Modernize	Upgrade core data systems and capabilities so fast, accurate, and complete data get to all levels of public health smoothly and seamlessly

Develop Community

Lead
- Identify strong leadership from within the community representing a diversity of perspectives

Align
- Ensure data harmonization efforts are aligned and coordinated to prevent redundancy and misalignment of needs

Listen
- Hear what the community is saying about the data sharing pain points and where they see FHIR playing a role

Core Principles

High Value and High Impact

Align With and Address Gaps in Core FHIR Capabilities

Feasible Within A Year
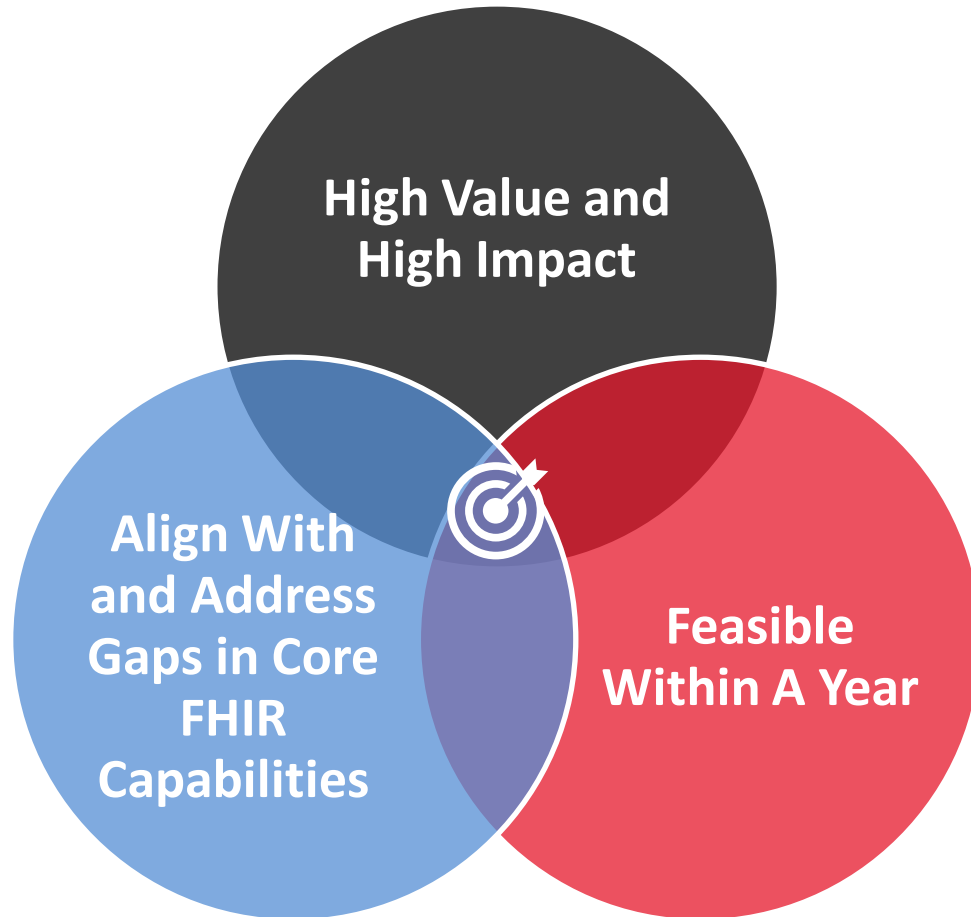
Desirability: Serves an immediate and pressing public health need.

Feasibility: Initial scope can be accomplished within a year.

Compatibility: Prioritize and address deviations in public health implementations of FHIR.

HELIOS

Deliver Aggregate Information to Public Health

Make Data in Public Health Systems Accessible in Bulk

Align and Optimize Public Health Data Sharing

Leads:

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Leads:

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Mary Beth Kurilo (AIRA)

Leads:

Michelle Barber (Oregon)

Steven Hill (Cerner)

Gillian Haney (CSTE)

HELIOS

Align and Optimize Public Health Data Sharing

Summary

How might public health access and exchange patient-level data more efficiently and effectively using FHIR to deliver the greatest net benefit overall?

Public Health Goals That Could Be Achieved

➢ Lay the groundwork to help provide more complete and up to date data to public health that would not be available easily under existing data channels

➢ Provide access (via push or pull as appropriate) to specific information needed to take public health action (for example, information needed to help understand the severity of illness and examine risk factors for severe disease across a population) as authorized and agreed upon

Project Team Objectives

➢ Explore options for sharing data with public health and returning actionable information to care providers

➢ Describe a process for assessing the interoperability needs of a use case and identifying optimal FHIR-based approaches for achieving data sharing

90-Day Goals (and Beyond)

➢ Explore available FHIR exchange paradigms (e.g., RESTful API Query, messaging, subscriptions) to better understand the capabilities they offer to public health

➢ Evaluate how a small number of high priority use cases can adopt these paradigms to develop concrete examples which resonate with public health and implementers

➢ Create the technical artifacts necessary to pilot use case solutions

HELIOS

Make Data in Public Health Systems Accessible in Bulk

Summary

How can data stored in public health information systems, such as IIS, be more accessible to authorized "B2B" users beyond public health (e.g., State Medicaid programs, healthcare partners, private insurers, etc.)?

Public Health Goals That Could Be Achieved

➢ Ensure authorized users of IIS data have a standardized pathway to access information (in bulk) on patient immunization histories to help address gaps in care while lowering burden on state public health agencies.
➢ Help health providers and payers to proactively support their patient and member populations.
➢ Increase coverage rates through improved access to complete, accurate information

Project Team Objectives

➢ Develop guidance for bulk FHIR query from an IIS that can eventually grow into a balloted Implementation Guide
➢ Leverage current tools, guidance, and reference implementations including work performed by the AIRA/HIMSS Immunization Integration Program (IIP)
➢ Socialize guidance and build investment across the IIS and immunization data exchange community

90-Day Goals (and Beyond)

➢ Define use cases for bulk data exchange
➢ Describe the architecture necessary to make IIS data available in bulk
➢ Evaluate the existing FHIR Bulk IG relative to public health needs
➢ Pilot bulk data exchange between IIS and authorized users in their jurisdiction

HELIOS

Deliver Aggregate Information to Public Health

Summary

What can we do to lessen the strain on health care and public health during times when both systems are most taxed (and configure the solution in a way so that it can also be used during "normal" operations)?

Public Health Goals That Could Be Achieved

➢ Provide mission-critical aggregate information (e.g., bed count, supply inventory) to public health during pandemics, natural disasters, and other preparedness events
➢ Use the same "building blocks" for aggregating information to help improve ongoing situational awareness and surveillance of non-reportable diseases, chronic conditions, birth defects, environmental health, and injuries during "normal" operations

Project Team Objectives

➢ Focus on the reporting of sentinel indicator measures comprised of rolled up, summary data (not the large-scale line-level data for individuals that formed the basis for deriving the summary data) that can enable identification and response to public health and other emergencies
➢ Establish an infrastructure for exchanging sentinel indicator measures, independent of the content of a given measure

90-Day Goals (and Beyond)

➢ Evaluate existing aggregate reporting standards (e.g. SANER and DaVinci DEQM FHIR IGs) for adoption
➢ Identify the likely sources of data for measures
➢ Implement pilot exchanges

HELIOS

Get Involved

Work alongside partners from across healthcare, government, and the private sector to access & exchange detailed information not easily available now

Learn more about Helios priority areas for 2022:
https://confluence.hl7.org/display/PH/2022+Use+Cases

Join a Helios project team, email:
helios@hl7.org

HELIOS

USCDI+ for PH

USCDI+ for Public Health Update

9/9/2022

USCDI+ for Public Health: Goals and Objectives

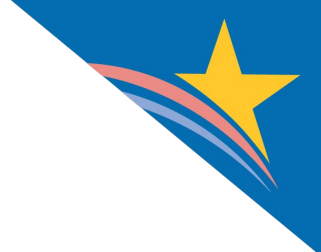- ONC and CDC are establishing the USCDI+ for public health to address core data and interoperability for public health needs beyond the scope of USCDI.

- Capture the data needs of public health that fall outside the scope of USCDI core and aim to **improve data quality and availability, helping to save time and resources for end users and PH officials**.

- Enable health IT vendors to send more consistent, harmonized data to improve **the quality of data available to public health to conduct disease surveillance and disease investigation.**

- Establish datasets that can support **a unified response across local partners, jurisdictions, and all levels of government.**

- Follow a more flexible and rapid lifecycle than USCDI, **allowing flexibility to meet changing and emerging needs of public health.**

Initial Sub-Domains

USCDI+ will leverage sub-domains to help ensure that the appropriate data elements are prioritized to support solutions to common public health data challenges.

- **Case-based Surveillance**: Crucial data elements received from clinical providers in order to conduct a case investigation and follow-up with a patient.

- **Lab Data Exchange:** Electronic orders and test results (ETOR), reporting of suspect cases, reporting point of care and at-home testing results to PH), and other more traditional lab data exchange immunization systems & vital records

- **Multi-Directional Exchange with Healthcare and Other Partners:** Facilitate automated, bi-directional information flows between healthcare, public health, and other authorized users for core surveillance areas such as lab and case data, immunizations, and vital records.

- **Maternal and Child Health**: Ability to receive all data elements to understand how maternal health may impact outcomes in both mother and child.

- **Resource reporting / Situational Awareness**: Data informing public health of resources available across a region to inform guidance and decision making.

- **Risk Behaviors and Drivers of Inequity:** Crucial data elements on risks and drivers of inequity for leading health conditions, such as physical activity as a vital sign, vulnerability indices and systematic race and ethnicity reporting, and medical outcomes of consequence.

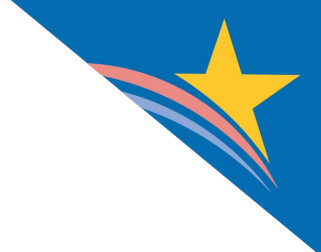# Overview of CDC Data Harmonization Process

CDC's USCDI+ Submission

Subdomains	Use cases	# Data Elements
Multi-Directional Exchange with Healthcare and Other Partners	Bi-Directional Referrals	50
	EHR-Based Chronic Surveillance	15
	Community and Clinical Linkages	36
	Data Exchange between IIS and Disease Surveillance Programs	20
	Data Exchange between IIS and Systems that Define Coverage Population (Vital Records, Refugee, etc.)	19
	Consumer Access to Immunization Information Systems	12
Case-Based Surveillance	Case reporting (general)	100
Laboratory Data Exchange	Laboratory Data Exchange (General)	2
Maternal and Child Health (General)	Maternal and Child Health (General)	2
Resource Reporting & Situational Awareness	Hospital Aggregate Patient Demographics Reporting	7
	Hospital Aggregate Morbidity Reporting	9
	Event-Associated Flows of Hospitalized Patients	13
	Hospital Bed Capacity and Availability	18
	Hospital Identifiers and Hospital Type	4
Risk Behaviors and Drivers of Inequity	Package SDH Data for Uses Beyond the Point of Care	62

CDC's USCDI+ Activities

1. Identified data elements currently available in USCDI v3, v2, v1 that map to priority use cases
2. Identified data elements submitted but not published in final versions (e.g., classified at level 1, 2, Comment)
3. Identified data elements beyond USCDI submissions
   - available in systems, IGs, MMGs, etc.
4. Compiled data elements
5. Determined priority data elements for USCDI+
6. Documented supporting evidence for data elements using template
7. Consolidated and shared with partners for review and comment
8. Submitted via USCDI+ ONDEC system

ONDEC+

National Coordinator for Health Information Technology (ONC)

ISA Content | ISA Publications | Recent ISA Updates | USCDI | SV

You are viewing USCDI as General Public. **View USCDI+ as a strategic partner**

View   New draft   Delete   Revisions

United States Core Data for Interoperability (USCDI)

The United States Core Data for Interoperability (USCDI) is a standardized set of health data classes and constituent data elements for nationwide, interoperable health information exchange. Review the USCDI Fact Sheet

A USCDI "Data Class" is an aggregation of various Data Elements by a common theme or use case.

A USCDI "Data Element" is the most granular level at which a piece of data is exchanged.

For example, Date of Birth is a Data Element rather than its component Day, Month, or Year, because Date of Birth is the unit of exchange.

USCDI ONC New Data Element & Class (ONDEC) Submission System

With the publication of USCDI v3, ONC is accepting submissions for new data elements through the ONDEC system and comments on existing data elements until September 30, 2022. ONC plans on releasing

| USCDI V1 | USCDI V2 | USCDI V3 | Level 2 | Level 1 | Comment |

Please reference the USCDI version 1 document to the left for applicable standards versions associated with USCDI v1.

Home > USCDI+

USCDI+

Public Health

Quality Measurement Domain

United States Core Data for Interoperability (USCDI) +

View   New draft   Delete   Revisions

USCDI+

USCDI+ is a service that ONC provides to federal partners who have a need to establish, harmonize, and advance the use of interoperable any questions, technical issues, or need to request access for a colleague, please email USCDI.Plus@hhs.gov

A USCDI+ "Domain" is a common set of data elements required for interoperability for multiple scenarios and use cases governed

A USCDI+ "Data Class" is an aggregation of various Data Elements by a common scenario or use case.

A USCDI+ "Data Element" is the most granular level at which a piece of data is exchanged.

For example, Date of Birth is a Data Element rather than its component Day, Month, or Year, because Date of Birth is the unit of

USCDI+ ONC New Data Element & Class (ONDEC) Submission System

Public Health Domain

ONC and CDC are establishing the USCDI+ for public health to address core data and interoperability for public health needs beyond the scope of USCDI. USCDI+ for public health intends to establish datasets that can support a unified response across local partners, jurisdictions, and all levels of government

Visit Public Health Domain

Quality Measurement Domain

To support the USCDI+ Quality Domain, ONC and CMS are establishing a data model reflecting the current universe of CMS's electronic clinical quality measures (eCQMs) that will support development of FHIR profiles and implementation guides for use in the ONC health IT certification program.

Visit Quality Measurement Domain

tps://www.healthit.gov/isa/form/uscdi-plus-submission-webform

HealthIT.gov
Interoperability Standards Advisory (ISA)

Home | **About the ISA** | **ISA Content** | **ISA Publications** | **Recent ISA Updates** | **USCDI** | **SVAP**

You are viewing USCDI+ as a strategic partner. **View USCDI as General Public**

USCDI+

USCDI+	−
Public Health	−
Case-Based Surveillance	+
Laboratory Data Exchange	+
Maternal and Child Health	+
Multi-Directional Exchange and Data Linkages	+
Resource Reporting & Situational Awareness	+
Risk Behaviors and Drivers of Inequity	+
Quality Measurement Domain	

View   Edit   Delete

Public Health Domain

ONC and CDC are establishing the USCDI+ for public health to address core data and interoperability for public health needs beyond the scope of USCDI. USCDI+ for public health intends to establish datasets that can support a unified response across local partners, jurisdictions, and all levels of government

USCDI+
ONDEC Submission System

Multi-Directional Exchange with Healthcare and Other Partners

Immunizations

Bi-Directional Referrals

EHR-Based Chronic Surveillance

Community and Clinical Linkages

Data Exchange between IIS and Disease Surveillance Programs

Data Exchange between IIS and Systems that Define Coverage Population (Vital Records, Refugee, etc.)

Consumer Access to Immunization Information Systems

Bidirectional Referral to CDC lifestyle change programs

Visit Multi-Directional Exchange with Healthcare and Other Partners

Case-Based Surveillance

Reporting to CDC (NNDSS)

Case Based Surveillance (General)

Visit Case-Based Surveillance

Laboratory Data Exchange

Laboratory Data Exchange (General)

Visit Laboratory Data Exchange

Maternal and Child Health

Maternal and Child Health (General)

Visit Maternal and Child Health

Resource Reporting & Situational Awareness

Hospital Aggregate Patient Demographics Reporting

Hospital Aggregate Morbidity Reporting

Event-Associated Flows of Hospitalized Patients

Hospital Bed Capacity and Availability

Hospital Identifiers and Hospital Type

Visit Resource Reporting & Situational Awareness

Risk Behaviors and Drivers of Inequity

Risk Behaviors and Drivers of Inequity (General)

Visit Risk Behaviors and Drivers of Inequity

Home > USCDI+ > Public Health > Case-Based Surveillance > Case Based Surveillance (General)

View   Edit   Delete

Case Based Surveillance (General)

USCDI+

Public Health

Case-Based Surveillance

Case Based Surveillance (General)

- Encounter Information - Case Based Surveillance (General)
- Travel Information - Case Based Surveillance (General)
- Work Information - Case Based Surveillance (General)
- Facility Level data - Case Based Surveillance (General)
- Immunizations - Case Based Surveillance (General)
- Medications - Case Based Surveillance (General)
- Observations
- Orders - Case Based Surveillance (General)
- Patient Demographics - Case Based Surveillance (General)
- Problems - Reporting to CDC (NNDSS)
- Procedures - Case Based Surveillance (General)
- Referral - Case Based Surveillance (General)

Reporting to CDC (NNDSS)
Laboratory Data Exchange
Maternal and Child Health
Multi-Directional Exchange and Data Linkages
Resource Reporting & Situational Awareness
Risk Behaviors and Drivers of Inequity

Quality Measurement Domain

Level 2   Level 1

Medications - Case Based Surveillance (General)

Date Medication Prescribed

Date Medication Prescribed

Medication Administered Performer

Medication Administered Reason Reference

Medication Prescribed Code

Medication Prescribed Dose

Medication Prescribed Dose Units

Medications Dispensed

Problems - Case Based Surveillance (General)

Information about a condition, diagnosis, or other event, situation, issue, or clinical concept that is documented.

Date of Resolution

Facility Level data - Case Based Surveillance (General)

Facility Managing Organization Identifier

Work Information - Case Based Surveillance (General)

Job Work Classification

Usual Occupation Duration

Usual Occupation Start Date

Patient Demographics - Case Based Surveillance (General)

Medicare Patient Identifier

Sex (Assigned at Birth) [Case Based Surveillance (General)]

Sexual Orientation

Observations

Observation Value

Procedures - Case Based Surveillance (General)

An activity that is performed with or on a patient as part of the provision of care.

Procedure Timing

Referral - Case Based Surveillance (General)

Reason for referral [Case Based Surveillance (General)]

Immunizations - Case Based Surveillance (General)

Record of an administration of a vaccination or a record of a vaccination as reported by a patient, a clinician, or another party.

Reason Immunization Not Performed

Vaccination event record type (administered/historical)

Vaccination Event Record Type (CBS)

Vaccine dose volume units [Case Reporting (General)]

Orders - Case Based Surveillance (General)

Types of orders for medical care/services

Comment

Overview of Review Process

Review Process

- USCDI+ differs from USCDI in that the feedback process is rolling, monthly incorporation of feedback.

- USCDI+ is currently is serving as an exploratory process to arrive at data-sets representing foundational PH needs.

- Goal is to provide a formal forum for:
  - Public health to express what data is necessary for their daily, mission-critical, functions.
  - Industry to respond and provide feedback on what data is/is not available to meet PH needs.
  - Identify paths forward to remedy gaps.

- Feedback/comment process is by invitation only. If anyone is interested/know of stakeholders that should get access, please email: USCDI.Plus@hhs.gov

Questions and Discussion