USCDI+ for Maternal Health

Pregnant Women and Lactating Women (PRGLAC): Implementation Working Group (WG)

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Agenda

1. ONC Overview
2. US Core Data for Interoperability (USCDI) Overview
3. USCDI+ for Maternal Health Initiative and Draft Data Set
4. Next Steps

ONC Overview

Office of the National Coordinator for Health IT

- Founded in 2004 by executive order, established in statute in 2009
- ONC is charged with formulating the **federal government's health IT strategy** to advance national goals for better and safer health care through an **interoperable nationwide health IT infrastructure**


HITECH Act 2009

21st Century Cures Act 2016

Laying the foundation of EHRs across the industry

- Investment to subsidize EHRs for hospitals and ambulatory providers
- ONC certification of EHR systems to support CMS and CDC programs

Leveraging EHRs to drive value

- Information blocking: Prohibits providers, technology developers, and health information networks from interfering with access, exchange, and use of electronic health information
- Standards: Data and API standards for access "without special effort"
- TEFCA: Nationwide governance for health information exchange networks – Trusted Exchange Framework and Common Agreement
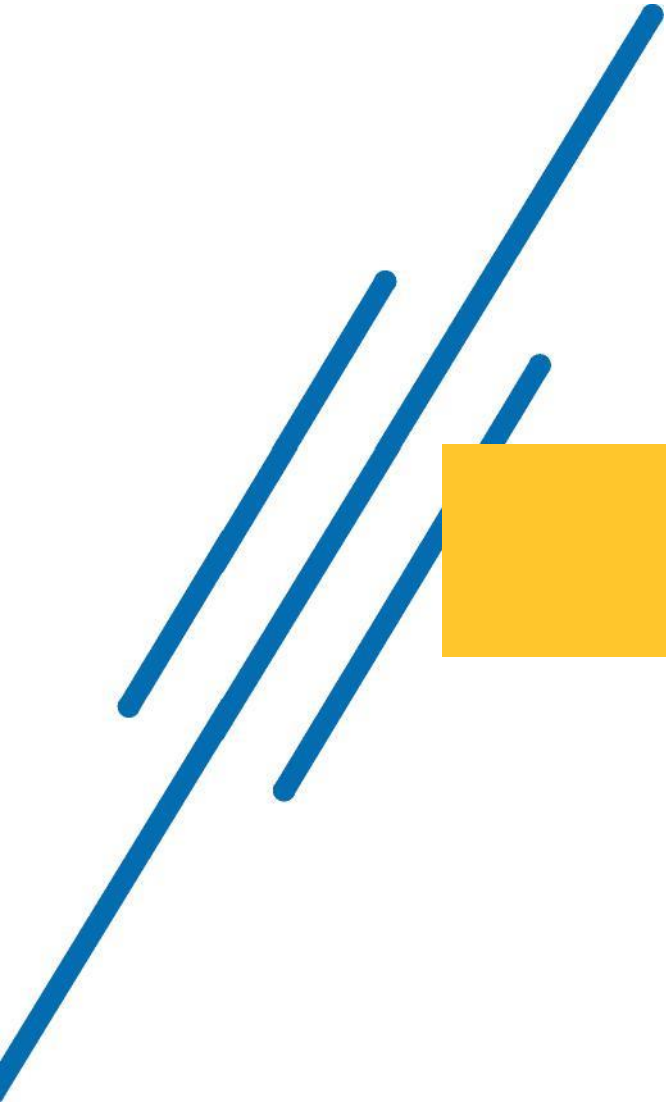
USCDI Overview

USCDI Essentials

USCDI

Establishes a consistent baseline of harmonized data elements that can be broadly reused across use cases to support patient care, facilitate patient access using health IT as well as other use cases.

Expands incrementally over time via a transparent, established, and collaborative process, weighing both anticipated benefits and industry-wide impacts.

Is required for Certification in the ONC Health IT Certification Program: standards-based application programming interface (API) to access patient data.

Is required by other HHS Programs as well: In 2020, CMS finalized API requirements for payers using USCDI

# USCDI: United States Core Data for Interoperability

USCDI v1 Summary of Data Classes and Data Elements

Allergies and Intolerances
- Substance (Medication)
- Substance (Drug Class)
- Reaction

Assessment and Plan of Treatment
- Assessment and Plan of Treatment

Care Team Members
- Care Team Members

Clinical Notes
- Consultation Note
- Discharge Summary Note
- History & Physical
- Imaging Narrative
- Laboratory Report Narrative
- Pathology Report Narrative
- Procedure Note
- Progress Note

Goals
- Patient Goals

Health Concerns
- Health Concerns

Immunizations
- Immunizations

Laboratory
- Tests
- Values/Results

Medications
- Medications

Patient Demographics
- First Name
- Last Name
- Previous Name
- Middle Name (incl Middle Initial)
- Suffix
- Birth Sex
- Date of Birth
- Race
- Ethnicity
- Preferred Language
- Current Address
- Previous Address
- Phone Number
- Phone Number Type
- Email Address

Problems
- Problems

Procedures
- Procedures

Provenance
- Author Time Stamp
- Author Organization

USCDI v2 Summary of Data Classes and Data Elements

Allergies and Intolerances
- Substance (Medication)
- Substance (Drug Class)
- Reaction

Assessment and Plan of Treatment
- Assessment and Plan of Treatment
- SDOH Assessment

Care Team Member(s)
- Care Team Member Name
- Care Team Member Identifier
- Care Team Member Role
- Care Team Member Location
- Care Team Member Telecom

Clinical Notes
- Consultation Note
- Discharge Summary Note
- History & Physical
- Procedure Note
- Progress Note

Clinical Tests
- Clinical Test
- Clinical Test Result/Report

Diagnostic Imaging
- Diagnostic Imaging Test
- Diagnostic Imaging Report

Encounter Information
- Encounter Type
- Encounter Diagnosis
- Encounter Time
- Encounter Location
- Encounter Disposition

Goals
- Patient Goals
- SDOH Goals

Health Concerns
- Health Concerns

Immunizations
- Immunizations

Laboratory
- Tests
- Values/Results

Medications
- Medications

Patient Demographics
- First Name
- Last Name
- Previous Name
- Middle Name (including Middle Initial)
- Suffix
- Sex (Assigned at Birth)
- Sexual Orientation
- Gender Identity
- Date of Birth
- Race
- Ethnicity
- Preferred Language
- Current Address
- Previous Address
- Phone Number
- Phone Number Type
- Email Address

Problems
- Problems
- SDOH Problems/Health Concern
- Date of Diagnosis
- Date of Resolution

USCDI v3 Summary of Data Classes and Data Elements

Allergies and Intolerances
- Substance (Medication)
- Substance (Drug Class)
- Reaction

Assessment and Plan of Treatment
- Assessment and Plan of Treatment
- SDOH Assessment

Care Team Member(s)
- Care Team Member Name
- Care Team Member Identifier
- Care Team Member Role
- Care Team Member Location
- Care Team Member Telecom

Clinical Notes
- Consultation Note
- Discharge Summary Note
- History & Physical
- Procedure Note
- Progress Note

Clinical Tests
- Clinical Test
- Clinical Test Result/Report

Diagnostic Imaging
- Diagnostic Imaging Test
- Diagnostic Imaging Report

Encounter Information
- Encounter Type
- Encounter Diagnosis
- Encounter Time
- Encounter Location
- Encounter Disposition

Goals
- Patient Goals
- SDOH Goals

Health Insurance Information
- Coverage Status
- Coverage Type
- Relationship to Subscriber
- Member Identifier
- Subscriber Identifier
- Group Number
- Payer Identifier

Health Status/Assessments
- Health Concerns
- Functional Status
- Disability Status
- Mental/Cognitive Status
- Pregnancy Status
- Smoking Status

Immunizations
- Immunizations

Laboratory
- Tests
- Values/Results
- Specimen Type
- Result Status

Medications
- Medications
- Dose
- Dose Unit of Measure
- Indication
- Fill Status

Patient Demographics/Information
- First Name
- Last Name
- Middle Name (Including middle initial)
- Name Suffix
- Previous Name
- Date of Birth
- Date of Death
- Race
- Ethnicity
- Tribal Affiliation
- Sex
- Sexual Orientation
- Gender Identity
- Preferred Language
- Current Address
- Previous Address
- Phone Number
- Phone Number Type
- Email Address
- Related Person's Name
- Related Person's Relationship
- Occupation
- Occupation Industry

Problems
- Problems
- SDOH Problems/Health Concerns
- Date of Diagnosis
- Date of Resolution

Procedures
- Procedures
- SDOH Interventions
- Reason for Referral

Provenance
- Author Organization
- Author Time Stamp

Unique Device Identifier(s) for a Patient's Implantable Device(s)
- Unique Device Identifier(s) for a patient's implantable device(s)

Vital Signs
- Systolic Blood Pressure
- Diastolic Blood Pressure
- Heart Rate
- Respiratory Rate
- Body Temperature
- Body Height
- Body Weight
- Pulse Oximetry
- Inhaled Oxygen Concentration
- BMI Percentile (2 - 20 years)
- Weight-for-length Percentile (Birth - 24 Months)
- Head Occipital-frontal Circumference Percentile (Birth- 36 Months)

USCDI+ Maternal Health Draft Data Set

USCDI+: Extending Beyond USCDI

- Unique agency or program-specific data systems and requirements are sometimes not fully met by USCDI
- ONC USCDI+ initiative helps government and industry partners build on USCDI to support specific program needs
- Applies USCDI processes for submission and harmonization while focusing on programmatic priorities
- Seeks to leverage programs and authorities across HHS to drive adoption
- Allows ONC to better serve federal partners, assures that extensions build from the same foundation, and creates the opportunity for aligning similar data needs across agency programs
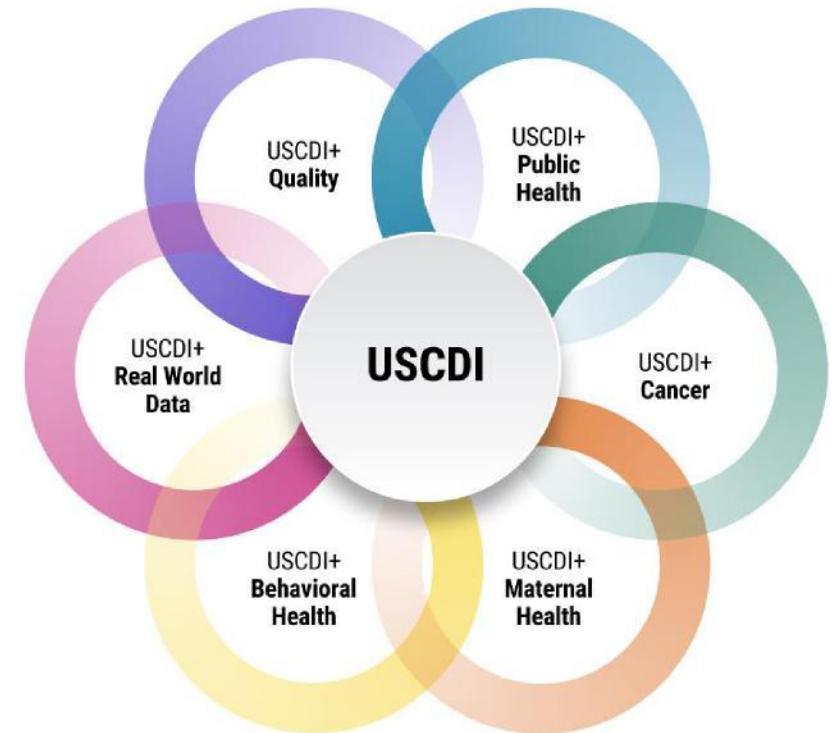
USCDI+ Maternal Health

- Goals of Draft Maternal Health Data Set
  - Establish a core set of data necessary for high quality care, equitable outcomes, and maternal health research
  - Facilitate standard implementation and support of core data for maternal health care within:
    - One or more implementation guides
    - Healthcare technology systems
- Data Set Inclusion or Exclusion Considerations
  - Importance for promoting high quality care and addressing care gaps
  - Likelihood of data availability through routine documentation
  - Potential implementation burden (e.g., electronic capture in discrete, structured fields)

Maternal Health Data Inputs and Key Sources

- Alliance for Innovation on Maternal Health (AIM) Patient Safety Bundles
- CMS Maternity Health Convening
- Federal Partner listening sessions with CDC, CMS, HRSA, NIH
- HL7 FHIR Implementation Guide: Longitudinal Maternal & Infant Health Information for Research (MHIG)
- Industry Partner Listening Sessions
- NQF Maternal Morbidity and Mortality Measurement Recommendations Final Report
- ONC Maternal Health Data Use Case and Standards Inventory (Version 1.0)
- Pilot Partners
- Pregnancy Risk Assessment Monitoring System (PRAMS) Questionnaire
- Severe Maternal Morbidity eCQM Methodology Report (SMM eCQM)
- USCDI
- Vital Records Birth and Fetal Death Reporting (in progress)
- White House Blueprint for Addressing the Maternal Health Crisis (MHB)

Questions to Gather Feedback

- Are these the right data classes and data elements? What's missing?

- What do you see that you're surprised to see and why?

- Any data in the draft data set that you think is problematic to capture or share?

- **HHS Program Offices**
  - Are there data that you collect or are important to collect that are not in the current draft?
  - Any insights from your experience in collecting any of this data?
- **Health Care Providers**
  - Do you capture this data in clinical documentation?
- **Health IT Developers**
  - Can the data elements be available for reporting in a national data set?
- **Public Health**
  - Are there additional data elements needed from a public health perspective?
- **Researchers**
  - Any additional data needed to support national research?
  - Any insights from your experience in collecting any of this data?

Overview of Current Maternal Health Data Set

- 163 data elements
  - 143 data elements in USCDI
  - 55 data elements shared with Public Health Domain
  - 65 data elements shared with Cancer Domain
  - 75 data elements shared with Quality Domain

- 13 Unique Maternal Health data elements (not in other domains or USCDI)
  - Examples:
    - Anxiety Screen, Depression Screen, Hemorrhagic Risk Screen Result
    - High Risk Perinatal Referral – Date, Reason, Type
    - Hypertensive Disorders of Pregnancy
    - Method of Contraception
    - Pregnancy Information

Sample of Common Data Elements Used in Obstetrics, Pharmacy, and Pediatrics

Dose	Amount of a medication for each administration.
Dose Unit of Measure	Units of measure of a medication. Examples include but are not limited to milligram (mg) and milliliter (mL).
Medications	Pharmacologic agent used in the diagnosis, cure, mitigation, treatment, or prevention of disease.
Medication Adherence	Statement of whether a medication has been consumed according to instructions. Examples include but are not limited to taking as directed, taking less than directed, and not taking.
Medication Instructions	Directions for administering or taking a medication. Examples include but are not limited to prescription directions for taking a medication, and package instructions for over-the-counter medications. Usage notes: May include route, quantity, timing/frequency, and special instructions (PRN, sliding scale, taper).
Birth Outcomes	The result of the subject's delivery, such as live birth or not a live birth.
Neonatal Abstinence Syndrome	Neonatal abstinence syndrome (NAS) is a withdrawal syndrome that can occur in newborns exposed to certain substances, including opioids, during pregnancy.
Gestational Age at Delivery	Gestational age at delivery refers to how far along the pregnancy is at delivery, generally expressed as a combination of weeks and days.
Multiple Birth Order	The sequence in which the baby was born, if part of a Delivery having multiple births. If not a single birth then the order born in the delivery, live born or fetal death (1st, 2nd, 3rd, 4th, 5th, 6th, 7th, etc.).
Ethnicity	Patient's self-identification as Hispanic/ Latino or Non- Hispanic/ Non-Latino.
Tribal Affiliation	Tribe or band with which an individual associates.
Race	An individual's response to the race question is based upon self-identification.

Mother – Infant Linkages

Findings

- Currently approaches to mom-infant record linkages vary by technology developer:
    - In some EHRs mom-infant records are linked when they are maintained in the same system
        - That link is broken when records are shared beyond the originating system
    - Some EHRs do not link mom-infant records
    - Some EHRs will create an encounter for mom-infant but records are not linked
        - When information about the infant is shared only mom's maiden name is shared
- Records have been linked using (not exhaustive list):
    - Infant date of birth
    - Next of kin information
    - Mother's demographics
    - Family history
    - HL7 FHIR resource RelatedPerson, Encounter.partOf, FamilyMemberHistory
    - HL7 V2 Patient Identification Segment (PID.21)

Next Steps

New HHS Policy on Alignment of Health IT Activities

- HHS Health IT Alignment Policy established in July 2022

- Secretary directs ONC to establish and oversee a consistent HHS-wide approach for:

  1. Incorporating **standard health IT requirements** language in all applicable HHS funding programs, contracts, and policies; and

  2. Providing direct ONC assistance to HHS agencies to **maximize the use of HHS-approved standards and authorities**

Contact ONC

📞 **Phone: 202-690-7151**

💬 **Health IT Feedback Form:** https://www.healthit.gov/form/healthit-feedback-form

🐦 **Twitter:** @onc_healthIT

💼 **LinkedIn:** Office of the National Coordinator for Health Information Technology

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