



Common Clinical Data Elements Project

(formerly known as Registries on FHIR)

PROJECT UPDATE

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Contributing Registries

American Academy of Ophthalmology
American College of Cardiology NCDR
American College of Gastroenterology
American College of Obstetricians and Gynecologists
American College of Radiology
American Optometric Association
American Orthopedic Association
American Physical Therapy Association
American Podiatric Medical Association
American Society for Clinical Pathology
American Society for Radiation Oncology
American Society of Anesthesiologists
American Society of Echocardiography
American Society of Nuclear Cardiology
American Urogynecologic Society
American Urological Association
Americas Hernia Society
Arthritis Research Center Foundation

Creaky Joints Patient Powered Research Network
Cystic Fibrosis Foundation
Michigan Surgical Quality Collaborative
National Osteoporosis Foundation
Neuropoint
North American Association of Central Cancer Registries
Outpatient Endovascular and Interventional Society
Plastic Surgery Registries Network (GRAFTS, TOPS)
Renal Physicians Association
Society for Vascular Surgery
Society of Interventional Radiology
Society of Thoracic Surgeons
University of Massachusetts Function & Outcomes Research for Comparative Effectiveness in Total Joint Replacement
United Network for Organ Sharing
Venous Access: National Guideline and Registry Development (VANGUARD)
Vermont Oxford Network
Women's Health Initiative

The Problem

- Inconsistency in collection of basic data
- Current model of data collection is manual chart abstraction and data re-entry aka “Swivel Chair Interoperability”
- This process is labor, time, and resource intensive
- Needed data elements are not available in source clinical documentation systems
- There is variation in structure, format and meaning, even among the same clinical concepts across different sources
- Results in lower data quality



Needs Addressed



Through voluntary consensus, standardizing key common clinical data elements used across electronic health information systems and registries to reduce burden and cost



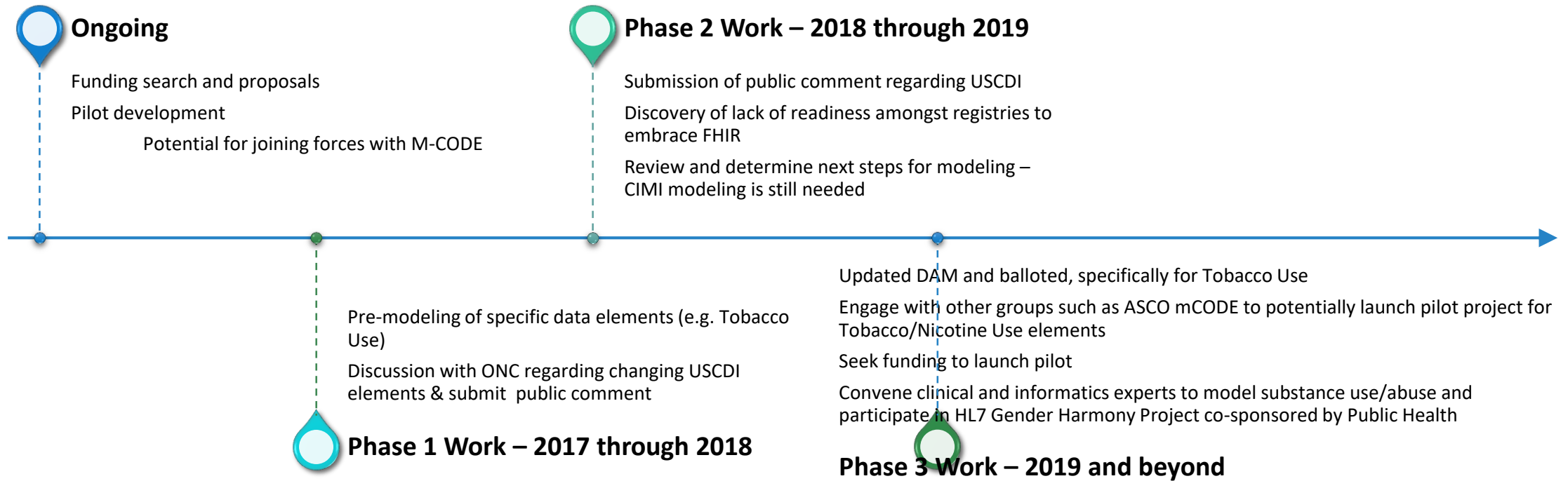
Aid in providing the clinical backbone for population health by enabling patient matching



Creation of an HL7 FHIR implementation guide to be made available for registries and source data systems to implement, reducing registry data collection costs more broadly.



Providing a consensus-based standard for national/international data collection



Timeline

Phase 1 – Data Collection

- Collection of case reports forms and other data dictionaries and artifacts from 37 registries
- Abstraction of a minimum of 20 data elements/concepts that were common across all the registries



Data Collection and Analysis

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Phase 2 – Data Normalization and Harmonization



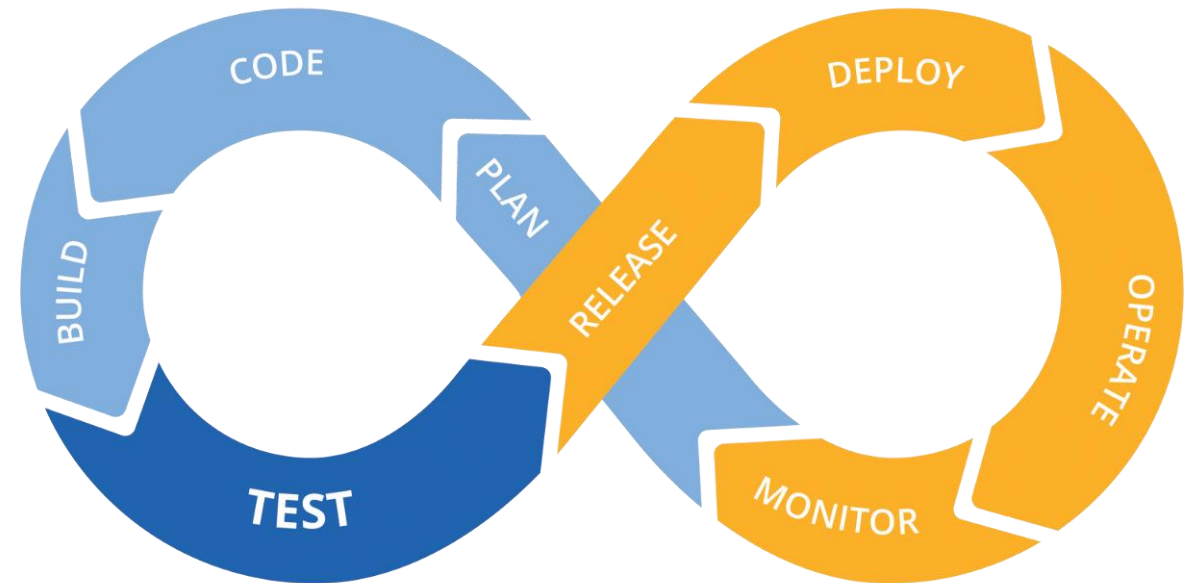
- Compare and harmonize these common data elements or concepts across:
 - National Data Standards and models [e.g The “Big 5” terminologies (SNOMED, LOINC, RxNorm, ICD, CPT)]
 - ONC Common Clinical Dataset / USCDI – OMOP / ODASI, SENTINEL, PCORNet – HL7 / HL7 FHIR]



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Phase 3 – Implementation

- Create Best Practice recommendations
 - “Lessons Learned” analysis
 - Improving existing data standards (Updating of US Core FHIR, USCDI)
 - Not creating an “Nth” Data Standard
- Creation of inputs to a roadmap that incorporates governance, structural, operational, and technical transformations for implementation (e.g. an implementation guide)
- Pilot Projects and incorporation of new common data elements
 - “Illicit drug use”/substance use/abuse
 - Collaboration with other harmonization projects



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Lessons Learned

- Lack of knowledge amongst registry operators of modeling technologies including FHIR
- Need for socialization, education and training to move to FHIR implementation
- Implementation and pilot phase is a moving target – we are flying to plane whilst building it
- Need for wide interdisciplinary group to ensure that modeling of data elements/concepts are uniform and universal (an area where CIIC can help)

Current Status and Next Steps



Work completed

- Close of Pew project
- Completion of CDEs
- Refine Tobacco Use data element
- Submit comment letter to ONC regarding USCDI
- Refine Tobacco Use data element
- Modeling Substance Use Data Elements
- Balloting Domain Analysis Model



Current and Upcoming work

- Modeling in CDA, V2, V3/CIMI related work
- Continued resolution of Domain Analysis Model ballot
 - Change of “Tobacco Use” to “Tobacco/Nicotine Product Use”
- Submission of outstanding codes to LOINC and SNOMED-CT
- Submission/updating in US Core FHIR
- Submission to USCDI specifically for Tobacco/Nicotine Product Use
- Engaging with ASCO m-CODE project to explore pilot project

Challenges

Ongoing change in needs

Refining data elements in light of USCDI changes

Unanticipated cost for modeling resources

Funding/Resources

Modeling in a timely fashion

Pre-modeling of specific data elements

Support for launching a pilot

Implementation

Recruitment for pilot

Proving the value of implementation

Philosophical Issues

Pre-coordination of data elements vs. post-coordination

Ensuring elements are universal

Anticipated CIIC Value/Support

- Value
 - Creation of clinical model for data elements to add to repository
 - Subject Matter Expertise
- Support
 - Modeling resources
 - Subject Matter Expertise
 - Identifying Funding Sources