



# Common Clinical Data Elements Project

(formerly known as Registries on FHIR)

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PROJECT UPDATE

OCTOBER 7, 2019

# Contributing Partners (not exhaustive)

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Lisa Anderson, TJC



# Contributing Registries

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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



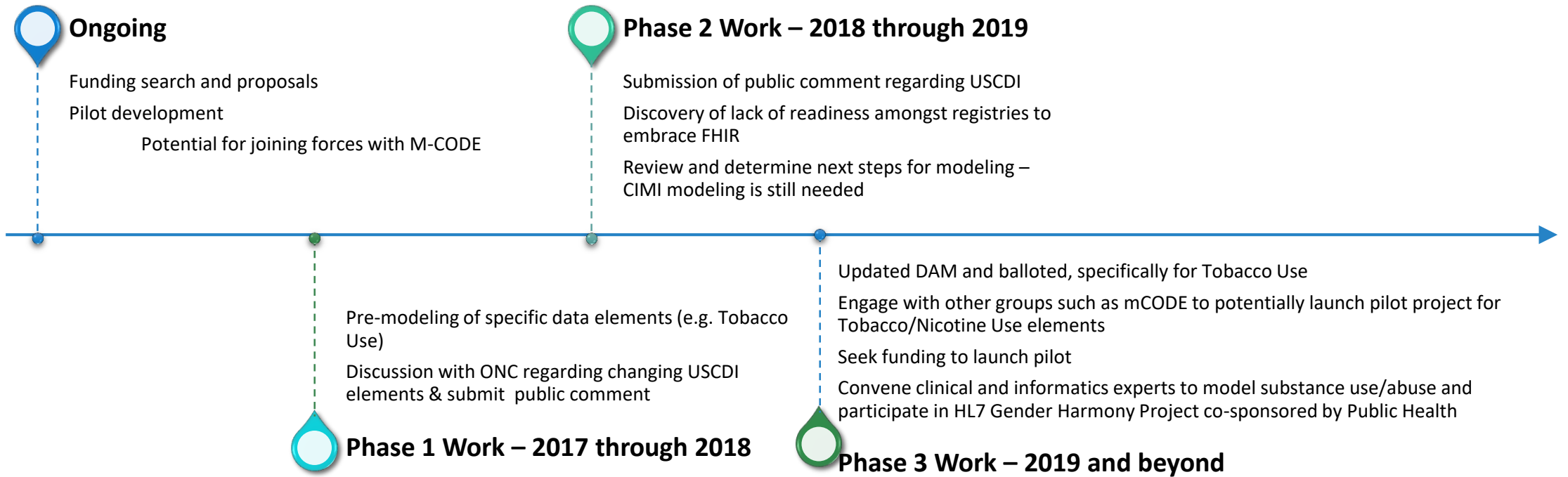
Aid in providing the clinical backbone for population health by enabling patient matching



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

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- Supported by Pew funded project in conjunction with Duke Clinical Research Institute
- 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]

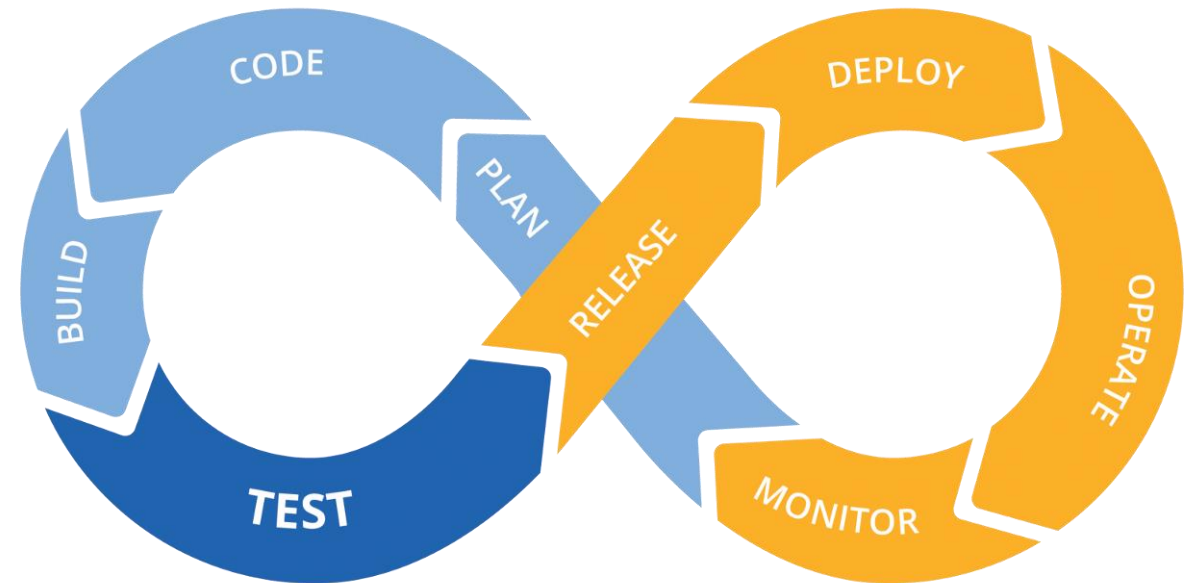


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# Phase 3 – Implementation

- 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 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 Logica Health can help)

# Current Status and Next Steps



## Work completed

- Close of Pew project
- Completion of CDEs
- Refined Tobacco Use data element
- Submitted comment letter to ONC regarding USCDI
- 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 m-CODE project to explore pilot project (Logica could help here)

# Challenges

## Ongoing change in needs

Refining data elements in light of USCDI changes and changes in science

Unanticipated costs

## 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/buy-in

## Philosophical Issues

Pre-coordination of data elements vs. post-coordination

Ensuring elements are universal

# Anticipated Value/Support

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