Central Cancer Registry Reporting (CCRR)

CCRR Health Level Seven (HL7®) Fast Healthcare Interoperability Resources (FHIR®) Implementation Guide (IG)

Ashley Knealing and Wendy Blumenthal

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Agenda

- Introduction to CCRR IG
- Development process of IG
- Changes from previous version
- IG navigation
- Use case and triggers
- Requirements and specifications
- Data elements
- Feedback requested
- Timeline and deadlines for feedback
- Next steps
- Q&A

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Introduction to CCRR IG

- FHIR is the future of standardized, electronic health information technology data exchange.
- The CCRR IG utilizes FHIR building blocks to advance central cancer registry reporting from Electronic Health Records (EHRs) in a standardized and structured format.
- The CCRR IG helps ensure central cancer registry data needs for content and data exchange are correctly represented.
- CDC, NAACCR, NCI, and ONC – ASTP are the multi-stakeholder groups using central cancer registry feedback to modify and refine the initial version of CCRR IG to include appropriate content and reporting triggers with a goal of real-time reporting.

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IG Development Background

- ONC-ASTP, NCI, CDC, and NAACCR participated in weekly meetings throughout early and mid 2025 to discuss incorporated data elements and FHIR resources, ensure correct mappings to NAACCR data items, review of content-based triggering and additional IG content.
- Focus group meetings with select registries (MD, NJ, UT, WI, AK, OH, WA, NC, CA) were held in May 2025 to gather feedback on content-based triggering and report timing.

Changes from Version 1(STU 1)

- Detailed content-based trigger requirements added
- Aligned with current versions of US Core, USCDI+ Cancer, and Cancer Pathology Data Sharing (CPDS) IG
- Removed relationship to MedMorph Reference Architecture IG
- Tightened requirements for these use case data elements:
  - Patient first and last name
  - Patient address state
  - Primary site and histology/behavior
  - Reporting Facility Identifier (NPI)
- Added CPDS Diagnostic Report Profile in specification
- The Standard for Trial Use (STU) 2 version of the IG is available for review starting December 15, 2025 until January 19, 2026.

IG Home Page and Navigation

- Introduction
- Table of contents

- Navigation ribbon

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Use Cases Page

- Background on Cancer Registry reporting
- Use Case
  - Problem statement: challenges, underreporting
  - Goal: automate the capture of cancer cases and cancer treatment information and provide incidence data faster for research and public health
  - Scope: collect standardized data on all types of reportable cancers
  - Triggers: **key section to review**; details on next slides
  - Actors and interactions: actor definitions and interactions
  - Reportability value sets: links to reportable condition codes

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Use Case Triggers and Reporting

- To limit the number of reports sent to registries, the IG contains specific reporting intervals and criteria for both encounter-based and content-based triggering to identify when to send a report to a central cancer registry.
- **Key triggers**:
  - Diagnosis (T0) (Encounter-based (EB) trigger)
    - Cancer diagnosis in standard reportability list
    - Initial report will be sent at T0 + 15 days if data elements present
    - OR at T0 + 30 days
  - EB triggers
    - Any encounter that meets the reportability criteria AND contains new information for: medications, procedures, or lab results
    - Medication and lab triggers based on cancer-related medication list (source: SEER*RX) and cancer-related lab test list
  - Non-encounter based (NEB) triggers
    - Added or updated information for: cancer diagnosis, stage, or radiation treatment

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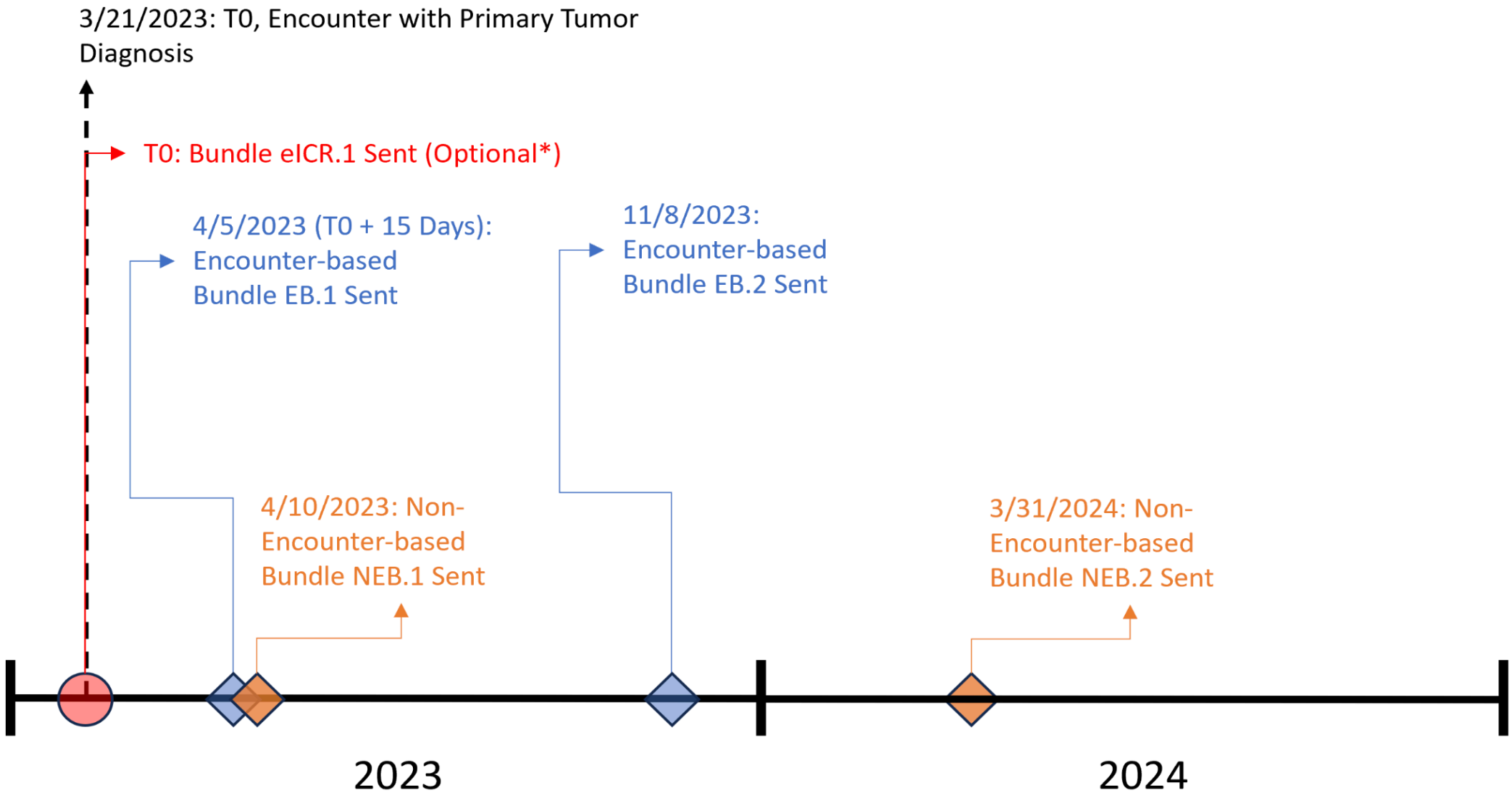
Patient Journey

- 38 y/o patient with triple negative breast cancer
- IG follows patient's diagnostic and treatment journey, identifying the triggers to report data to the central cancer at the time of each event to help complete the case summary and abstract
- Key triggers
  - Diagnosis of infiltrating duct carcinoma of left breast
  - Systemic treatment (chemotherapy medications)
  - Surgical treatment (lumpectomy)
  - Radiation treatment summary

Figure 2.1 - Sample Central Cancer Registry Reporting Timeline for the Patient Journey



Not shown: Encounters or other events that do not meet the CCRR IG triggering requirements.

https://build.fhir.org/ig/HL7/fhir-central-cancer-registry-reporting-ig/usecases.html

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Technical Requirements & Specifications

- Must Support Definition
  - Systems **SHALL** be capable of populating data elements as specified by the profiles
  - When data is not available for any of the mandatory elements specified in the IG, a data absent reason extension should be added to satisfy the requirement along with an appropriate value from the data-absent-reason value set
- Profiles and other IGs Usage
  - IG leverages the FHIR US Core IG wherever possible, which provides alignment with USCDI
  - Alignment with USCDI+ Cancer Use Case
  - IG leverages minimal Common Oncology Data Elements (mCODE) FHIR IG for exchanging cancer specific information
- For technical reviewers
  - Implementation Requirements
  - Data Source Requirements
  - Data Submitter Requirements
  - Data Receiver Requirements

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Data Elements Content Overview: **Read Me Tab**

- Feedback guidance: questions to consider
- Explanation of technical attributes
  - **Cardinality, Data Absent Reason, Must Support (MS)**
  - **IG status:** This field summarizes the different attributes and how they work together. This information is not directly in the IG.
- **Notes:** Technical details may look different in the IG for selected elements; we provide information in here in slightly different format for some elements for ease of understanding and review.
  - Technical reviewers can review data elements directly in IG through CCRR profiles and other leveraged profiles
  - Value sets/terminologies
    - Not included in spreadsheet
    - Can be found in IG profiles
    - Based on national and international standard terminologies used by EHRs
    - Conform with US Core and USCDI
    - Mapping to NAACCR standard will be implemented in software tools

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Data Elements Content Overview
Data Elements Tab (1)

- **Use case data element**: Conceptual name, may not match IG exactly
- **Description (FHIR):** Description of the data element in FHIR IG
- **Cancer IG Location:** for more technical reviewers, indicates where to find the data element in the IG, along with the profile links in section headings
- **NAACCR V25 Data Item # and Name:** provides the number and name of the data item in NAACCR that the FHIR element can be mapped to. Mapping will be updated to current version for software processing.

Data Elements Content Overview
Data Elements Tab (2)

- **Cardinality:** The minimum and maximum number of times an element can appear.
  - Minimum cardinality of 1 = required
  - Minimum cardinality of 0 = optional
  - Maximum cardinality of 1 = only one instance of the element
  - Maximum cardinality of * = infinite number of instances
- **Data Absent Reason:** Indicates if there is an option to provide a data absent reason when the data element is not provided in the report (Yes/No)
- **Must Support:** Indicates if the data element has a Must Support requirement (Yes/No)
- **IG Status:** a field that summarizes the different attributes and how they work together; information not explicitly in the IG

	Must Support = Present	Must Support = Absent
Cardinality = 0..1	• Data element (DE) not required to be populated • System must support DE	• DE not required to be populated • System not required to support DE
Cardinality = 1..1 or 1..*	• DE required to be populated • System must support DE	**Not applicable**

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Spreadsheet--Examples

- Patient Last Name
  - Required or Data Absent Reason must be provided
- Cancer Histology/Behavior
  - Required: either code or text must be provided
  - No data absent reason option
  - Single data element for histology and behavior; codes from ICD-O3 or SNOMED are allowed and can be mapped to both
- Procedure Code
  - Required **if** there is a procedure to report
  - Must Support

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Feedback requested

Basic instructions

- Alchemer survey will be emailed to all attendees on December 15, 2025
- Complete the survey, once it is available, on or before January 7, 2026
- Be as specific as possible (e.g., if you think wording needs to be changed, precisely propose the new wording)

What kind of feedback is needed from CCRs?

- Triggers
  - What information is critical to trigger a report that may be unclear or missing?
  - What additional information, if any, should be contained on the initial report?
  - What could/should be captured outside of first course of treatment (e.g., staging, final diagnosis, etc.)?
- Data elements spreadsheet
  - Any data elements missing?
  - Any data elements that you think should be excluded?
  - Any changes to required, data absent, optional, or must support data element attributes?
- Narrative (“informative”) content (home page, background, etc.)
  - Anything unclear or missing?
  - Anything you think should be added, removed, or modified?
- Request in person (virtually) if you would like to be present at the discussion around the resolution of your comment (optional).

Timeline & deadlines for feedback

HL7 Ballot process

- 12/14/25 - Final content freeze
- **12/15/25 – CCR Feedback begins**
- 12/19/25 - Ballot opens
- **1/7/26 - CCR feedback due to NAACCR**
- 1/19/26 - Ballot closes
- 1/20/26 - Ballot reconciliation begins

Next steps

- All IG comments will be submitted and tracked in Jira via the HL7 Confluence.
- Any comments submitted during open ballot period must be addressed during the ballot reconciliation process.
- Submitted comments will be discussed and dispositioned through the voting process on HL7's Public Health Work Group meetings.
- NAACCR and CDC will provide updates on the ballot reconciliation and IG publication process.
- Future testing of the IG is yet to be determined. Testing may consist of HL7 Connectathons and testing with central registries and central registry software vendors.
- The Registry Plus team is documenting a workflow and evaluating implementation strategies in Registry Plus software.