Cancer Reporting Use Case - DRAFT

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Description

The purpose of the use case is to transmit cancer case information to state Central Cancer Registries. The intent is to provide access to data not currently available, or available through non-standard and/or manual methods; it will not replace hospital registry reporting methods that are working well. The cancer use case will help assess how to address the gaps in workflow and triggers, and the potential to leverage existing HL7 FHIR Implementation Guides to address the public health information needs.

Problem Statement

Cancer is a mandatory reportable disease; every state has public health law/regulation requiring information to be reported to a central cancer registry about all cancers diagnosed or treated within that state. Central cancer registries are population-based cancer registries that collect data on all cancer cases in a defined population. The main sources of information include information from treatment facilities (e.g., hospitals, clinics /physician offices), diagnostic services (e.g., pathology laboratories) and vital statistics (e.g., death certificates). Central cancer registries have an emphasis on epidemiology and public health to determine patterns among various populations, monitor cancer trends over time, guide planning and evaluation of cancer control efforts, help prioritize health resource allocations and to advance clinical, epidemiologic and health services research.[1] Even with reporting requirements, cancer surveillance is complex given the heterogeneous nature of the disease, numerous diagnostic and prognostic factors, and multiple medical encounters that produce data from a variety of non-harmonized data sources.

Challenges include:

- issues with data flow
- delays in data availability
- a lack of standardized systems for cancer data collection and reporting (in some cases)

These challenges make it difficult for registries to synthesize information in a timely and actionable way.

Goals of the Use Case

The goal of this use case is to capture cases of cancer and cancer treatment information not reported by other sources and provide incidence data faster for research and public health. Additionally, this use case aims to identify data standards that allow for the collection, transmission, and aggregation of these data electronically from EHRs automatically rather than relying on labor-intensive manual processes, and duplications of effort.

Scope of the Use Case

In-Scope

- Collect standardized data on all types of reportable cancers diagnosed and/or treated
- Define under what circumstances an EHR system must create and transmit a cancer report to the central cancer registry
- Identify the data elements to be retrieved from the EHR to produce the cancer report
- Use NAACCR Volume II data dictionary for standardized data collection
- Include data collection along the longitudinal spectrum (Diagnosis -> Staging -> Initial Treatment -> Death)

Out-of-Scope

- Validation of the EHR data
- Data captured outside the EHR and communicated directly to registries
- Changes to existing provider workflow or existing data entry
- Policies of the clinical care setting to collect consent for data sharing
- Integrating claims data into the trigger event to send a report to the cancer registries

Use Case Actors

Electronic Health Record (EHR)[2] System: A system used in care delivery for patients and captures and stores data about patients and makes the information available instantly and securely to authorized users. While an EHR does contain the medical and treatment histories of patients, an EHR system is built to go beyond standard clinical data collected in a provider's provision of care location and can be inclusive of a broader view of a patient's care. EHRs are a vital part of health IT and can:

- Contain a patient's medical history, diagnoses, medications, treatment plans, immunization dates, allergies, radiology images, and laboratory and test results
- Allow access to evidence-based tools that providers can use to make decisions about a patient's care
- Automate and streamline provider workflow

A FHIR Enabled EHR exposes FHIR APIs for other systems to interact with the EHR and exchange data. FHIR APIs provide well defined mechanisms to read and write data. The FHIR APIs are protected by an Authorization Server which authenticates and authorizes users or systems prior to accessing the data. The EHR in this use case is a FHIR Enabled EHR.

Backend Services App: A system that resides within the clinical care setting and performs the reporting functions to public health and/or research registries. The system uses the information supplied by the metadata repository to determine when reporting needs to be done, what data needs to be reported, how the data needs to be reported and to whom the data should be reported. The term "Backend Service" is used to refer to the fact that the system does not require user intervention to perform reporting. The term "App" is used to indicate that it is similar to a SMART on FHIR App which can be distributed to clinical care via EHR vendor specified processes. The EHR vendor specified processes are followed to enable the Backend Services App to use the EHR's FHIR APIs to access data. The healthcare organization is the one who is responsible for choosing and maintaining the Backend Services App within the organization.

Central Cancer Registry: A PHA/Research organization and data repository that receives and stores cancer case information. Data Repositories are actively managed and are used to receive data, store data, and perform analysis as appropriate. These data repositories could be operated or accessed by PHA (or their designated organizations), research organizations with appropriate authorities and policies.

Cancer Reporting Process Abstract Model

Figure 1 below is the Abstract Model that illustrates the actors, activity, and systems involved in the Cancer Use Case workflow.

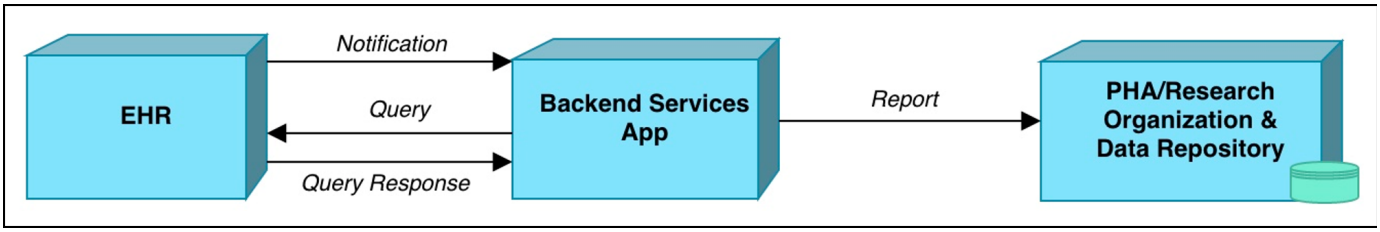

Figure 1: Cancer Reporting Process Abstract Model

Use Case User Stories and Diagrams

Preconditions

Preconditions describe the state of the system, from a technical perspective, that must be true before an operation, process, activity, or task can be executed. Preconditions are what need to be in place before executing the use case flow.

The preconditions for the cancer reporting use case include:

- Use Case Trigger: A cancer diagnosis has been recorded in the EHR
- EHR and central cancer registry systems support HL7 FHIR APIs
- Pertinent data elements are captured discretely in the EHR
- Public Health uses allowed by HIPAA and other statutory authorities have been defined and implemented
- Provisioning workflows have been established. The workflow includes activities that publish the various metadata artifacts required to make EHR data available to public health and/or research. These activities include publishing value sets, trigger codes, reporting timing parameters, survey instruments, structures for reporting etc. These artifacts are used subsequently in data collection and reporting workflows.

User Stories

User Story Cancer Diagnosis and Treatment - Reporting based on Specific Criteria

A patient visits her primary care provider (PCP) because of a lump in her breast. The provider orders a mammogram and then a biopsy that is sent to the pathology laboratory for testing. The laboratory analyzes the biopsy specimen which indicates the patient has breast cancer. The pathology report is sent to the provider who ordered the biopsy. The provider confirms the diagnosis of breast cancer. This information is integrated into the patient's clinical record. The patient is informed of her test results. The PCP's clinic EHR system determines that the patient has been diagnosed with a cancer that meets the criteria for reporting to the central cancer registry, as defined by the national standard Cancer Reportability List. A standard report with the required data elements is sent to the central cancer registry where the patient resides, as required by state law. The PCP orders a further workup and clinically stages the patient's cancer. The EHR system determines that staging information has not been previously submitted to the central cancer registry and meets the criteria for reporting. A standard report with the required data elements is sent to the central cancer registry where the patient resides, as required by state law.

The patient has surgery (not covered in this user story) and then PCP refers her to a medical oncologist in the same clinic for further treatment. The medical oncologist sends the patient to the radiation therapy department to initiate radiation therapy as part of the first course of treatment for her breast cancer. Radiation therapy is given and is documented in the EHR as the reason for the encounter/visit. The EHR system determines that the patient was seen for treatment of a cancer that meets the criteria for reporting to the central cancer registry and that this patient has not previously received this category* of treatment. A standard report with the required data elements is sent to the central cancer registry where the patient resides, as required by state law. As directed by the treatment plan, the patient returns to the cancer treatment center to receive the next radiation treatment session. Radiation is given and is documented in the EHR as the reason for the encounter/visit. The EHR system determines that this patient has received this category* of treatment and a report was already sent to the registry based on this category. Therefore, it does not generate a new report to send to the cancer registry.

After radiation, the medical oncologist initiates the chemotherapy regimen as part of the first course of treatment for her breast cancer. The chemotherapy drugs are infused, and the chemotherapy treatment is documented in the EHR as the reason for the encounter/visit. The EHR system determines that the patient was seen for treatment of a cancer that meets the criteria for reporting to the central cancer registry and that this patient has not previously received this category of treatment. A standard report with the required data elements is sent to the central cancer registry where the patient resides, as required by state law. As directed by the treatment plan, the patient returns to the cancer treatment center to receive the next chemotherapy cycle. The intravenous chemotherapy drugs are infused, and the chemotherapy treatment is documented in the EHR as the reason for the encounter/visit. The EHR system determines that this patient has received this category of treatment and a report was already sent to the registry based on this category. Therefore, it does not generate a new report to send to the cancer registry.

The medical oncologist prescribes hormone therapy for the patient, which is documented in the EHR. The EHR system determines that the patient was prescribed a treatment that meets the criteria for reporting to the central cancer registry and that this patient has not previously received this category of treatment. A standard report with the required data elements is sent to the central cancer registry where the patient

resides, as required by state law. As directed by the treatment plan, the patient gets prescribed the next dose of hormone therapy. The prescription is documented in the EHR. The EHR system determines that this patient has received this category of treatment and a report was already sent to the registry based on this category. Therefore, it does not generate a new report to send to the cancer registry.

After a certain period of time from a specified starting point (to be determined by the cancer registry), the EHR generates and sends a standard report with data elements (to be identified) to the central cancer registry where the patient resides.

*Category of treatment: Cancer-directed Procedures, Radiation, Chemotherapy, Hormone Therapy, Immunotherapy (Biological Response Modifier (BRM)), Refusal for Treatment, Watchful Waiting, Other cancer-directed therapy. (Note: These can all be provided in one or more value sets).

Cancer Diagnosis and Treatment Main Flow

The table below illustrates each actor, role, activity, input, and output of each step of the Cancer Diagnosis and Treatment user story.

Step	Actor	Role	Activity	Input(s)	Output(s)
1	EHR System	Notifier	Notify the Backend Service App that criteria have been met	Trigger code	Notification message
2	Backend Services App	Evaluator	Evaluate notification message against criteria	Notification message content	Continuation decision based on available information
3	Backend Services App	Data Extractor	Query the EHR for cancer data	Notification message	FHIR query
4	EHR System	Query Responder	Return cancer data	FHIR query	FHIR resources
5	*Backend Services App*	*Decision Logic Evaluator*	*Evaluate if a report needs to be sent*	*FHIR resources*	*FHIR resources*
6	Backend Services App	Data Receiver	Receive FHIR resources and validate FHIR bundle	FHIR resources	FHIR validated bundle
7	Backend Services App	Data Sender	Send validated FHIR bundle to Central Cancer Registry	FHIR validated bundle	FHIR validated bundle
8	Central Cancer Registry	Data Receiver	Receive and validate FHIR bundle	FHIR bundle	Validated FHIR bundle
9	Repeat Steps 1-8 *for any category notification that meets the reporting criteria as needed*				

Table 1: Cancer Diagnosis and Treatment Flow

Cancer Diagnosis and Treatment Activity Diagram

Figure 2 below illustrates the flow of events and information between the actors for the Cancer Diagnosis and Treatment workflow.

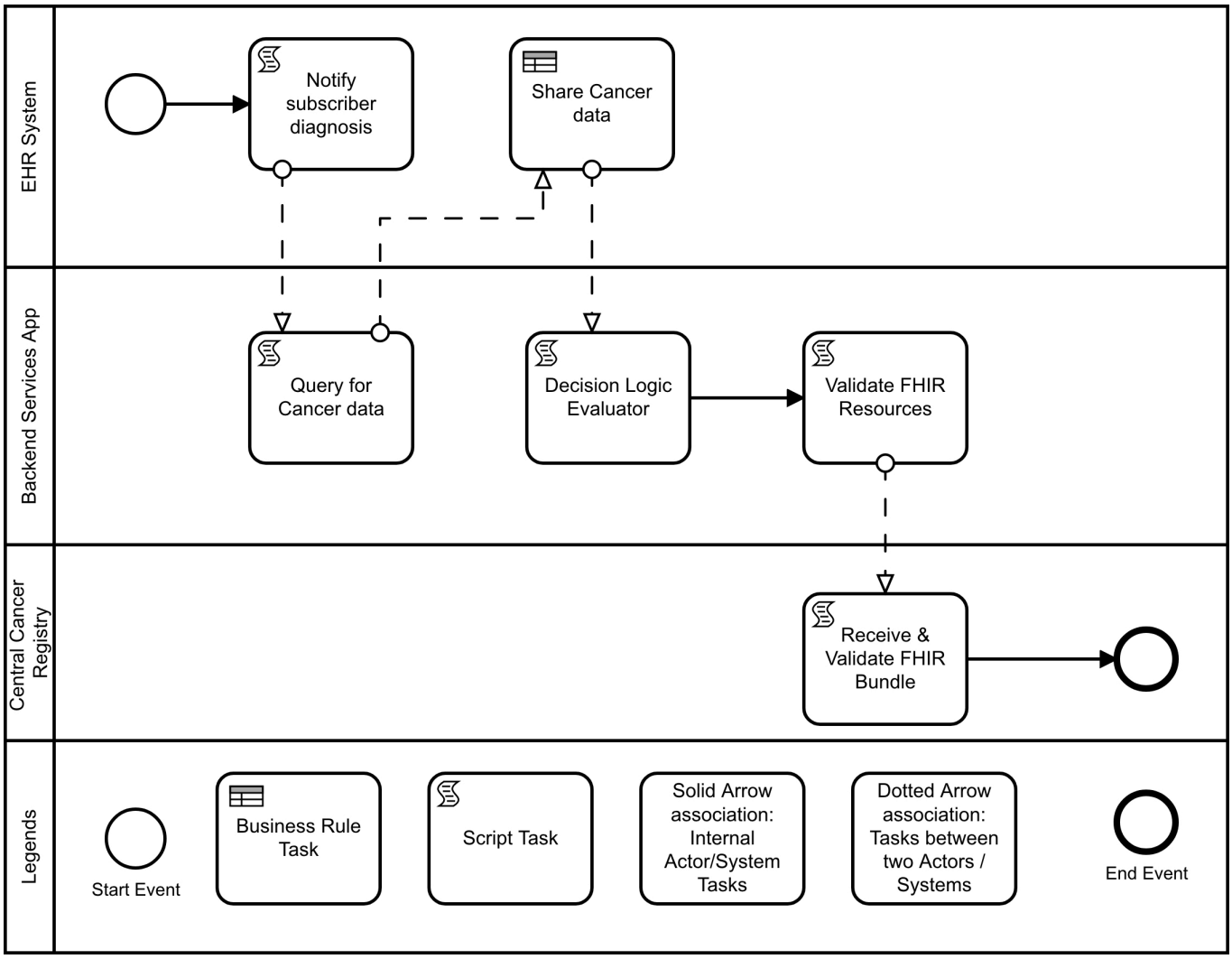

Figure 2: Cancer Diagnosis and Treatment Activity Diagram

Cancer Diagnosis and Treatment Sequence Diagram

Figure 3 below represents the interactions between actors in the sequential order that they occur in the Cancer Diagnosis Treatment workflow.

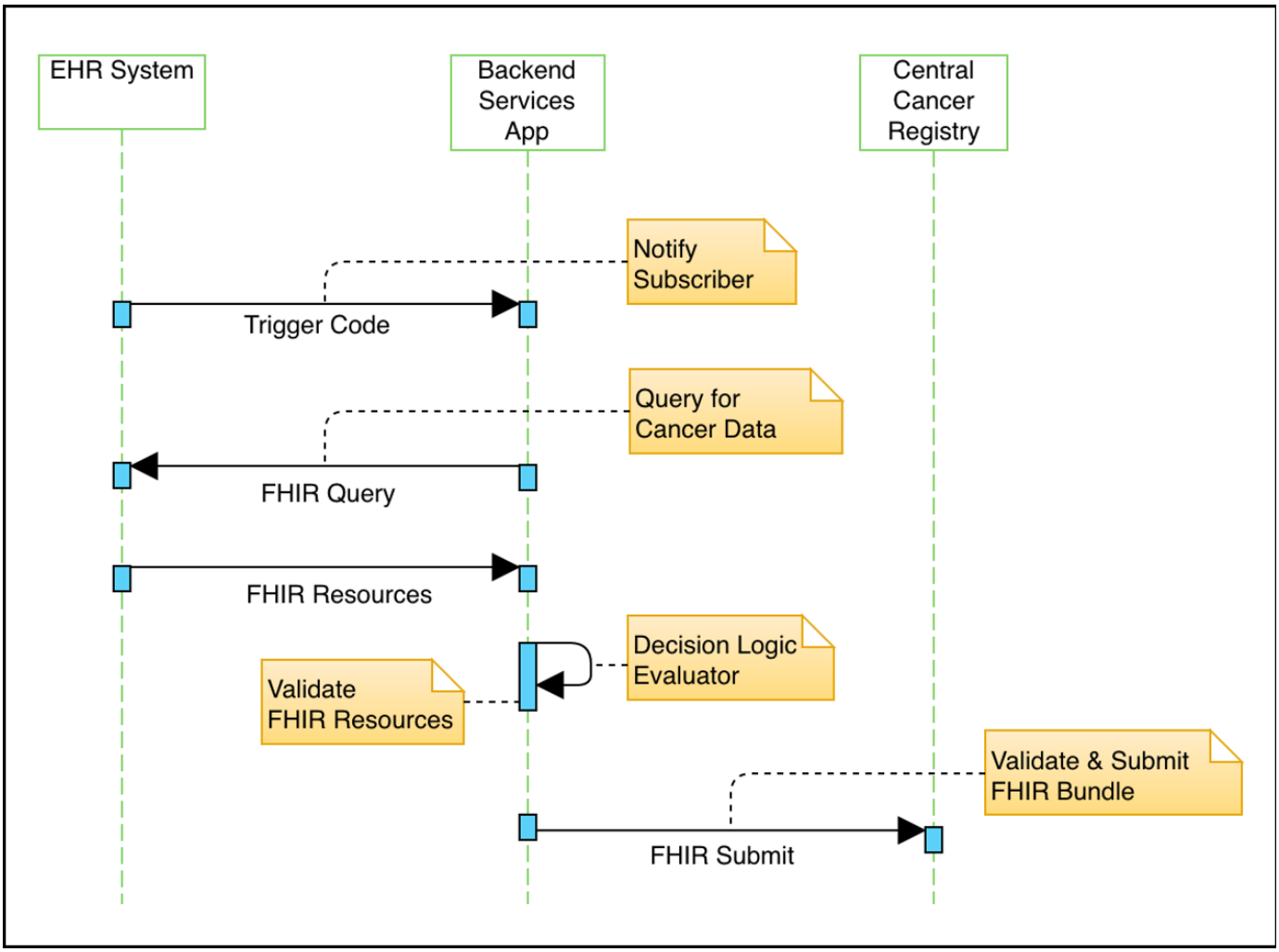

Figure 3: Cancer Diagnosis and Treatment Sequence Diagram

Alternate Flow – Reporting Every Encounter

Cancer - Reporting Every Encounter Alternate Flow

The Cancer Diagnosis and Treatment – Reporting Every Encounter user story remains the same as the Cancer Diagnosis and Treatment user story ***except*** instead of identifying a category of criteria that triggers a report, the "all reports" criteria are set.

The table below illustrates each actor, role, activity, input, and output of each step of the Alternate Cancer Diagnosis and Treatment Reporting Every Encounter user story

Step	Actor	Role	Activity	Input(s)	Output(s)
1	EHR System	Notifier	Notify the Backend Service App that criteria have been met	Trigger code	Notification message
2	Backend Services App	Evaluator	Evaluates notification message against criteria	Notification message content	Submittal decision based on available information
3	Backend Services App	Data Extractor	Query the EHR for cancer data	Notification message	FHIR query
4	EHR System	Query Responder	Return cancer data	FHIR query	FHIR resources
5	Backend Services App	Data Receiver	Receive and validate FHIR *resources*	FHIR resources	FHIR validated bundle
6	Backend Services App	Data Sender	Send validated FHIR bundle to Central Cancer Registry	FHIR validated bundle	FHIR validated bundle

7	Central Cancer Registry	Data Receiver	Receive and validate FHIR bundle	FHIR bundle	Validated FHIR bundle
8	Repeat Steps 1-7 *for all reports*				

Table 2: Cancer - Reporting Every Encounter Alternate Flow

Cancer - Reporting Every Encounter Activity Diagram

Figure 4 below illustrates the flow of events and information between the actors for the Cancer Diagnosis and Treatment - Reporting Every Encounter workflow.

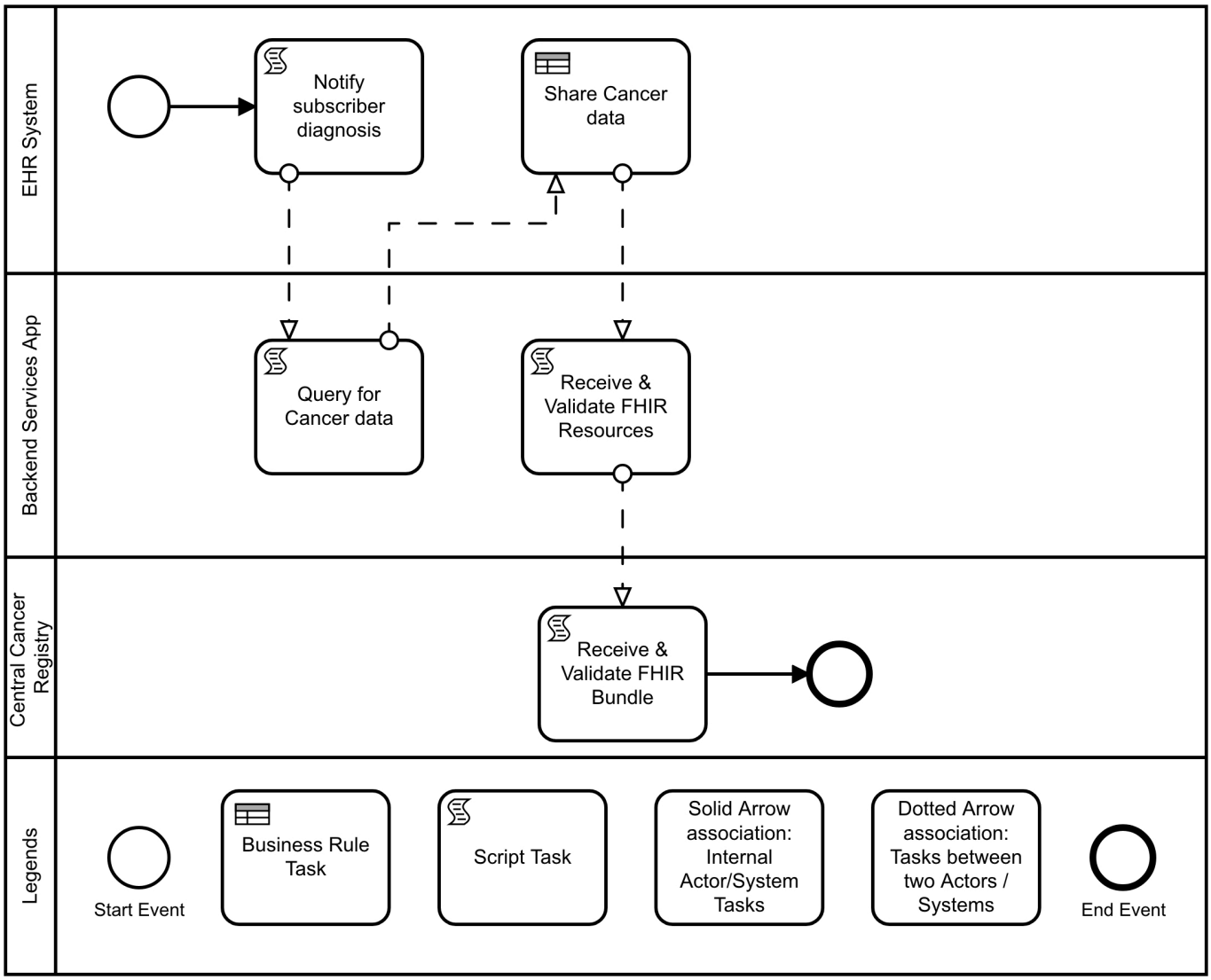

Figure 4: Cancer - Reporting Every Encounter Activity Diagram

Cancer - Reporting Every Encounter Sequence Diagram

Figure 5 below represents the interactions between actors in the sequential order that they occur in the Cancer Diagnosis and Treatment – Reporting Every Encounter workflow.

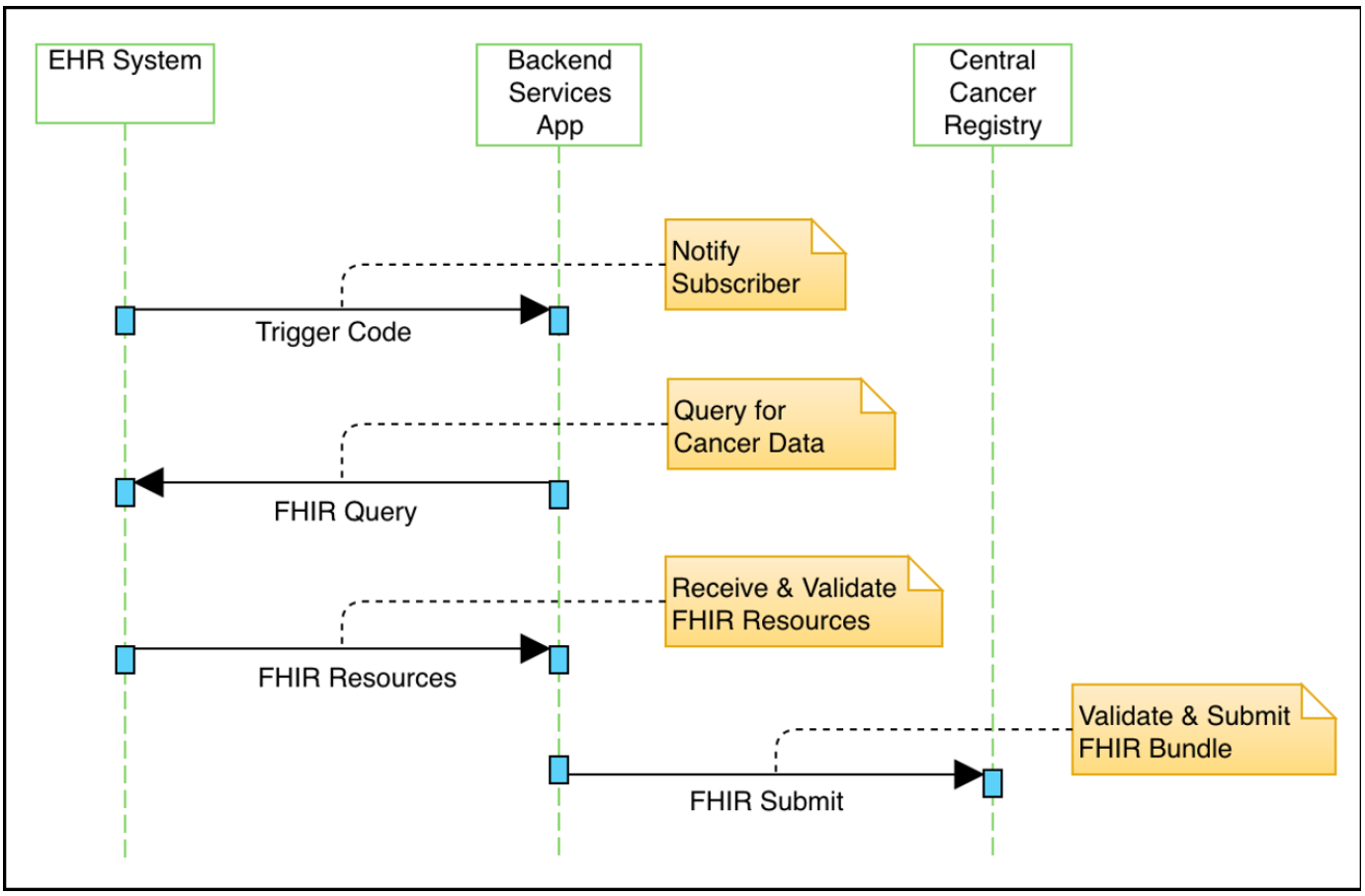

Figure 5: Cancer - Reporting Every Encounter Sequence Diagram

Postconditions

- The submitted cancer report resides in the central cancer registry.

Data Requirements

Cancer Data Elements: *Note that these are pulled from NAACCR Version 18 Data Standards and Data Dictionary.*

The table below illustrates the data element, definition, sample values or codes, USCDI, and USCDI element name for cancer reporting.

NAACCR Data Item #	NAACCR Data Item Name	Use Case Data Element Name	Definition	USCDI V1 Data Class	USCDI V1 Data Element	US Core Profile / FHIR Resource	US Core / FHIR element	Sample Value	Sample Value Display Name	Code System OID	Code System Name	Value Set OID
2110	Date Case Report Exported	Date Report Generated	effectiveTime (Date Document was Generated)									
		? Not sure what to call this; does FHIR have an equivalent concept?	CDA Element: setId									
		Version Number	CDA Element: Version Number					1				
Patient Information												
2330	Name--Last	Patient Last Name	Last name of the patient.	Patient Demographics	Last Name	US Core Patient Profile	Patient.name.family	Shepherd				
2240	Name--First	Patient First Name	First name of the patient.	Patient Demographics	First Name	US Core Patient Profile	Patient.name.given	Meredith				

2250	Name--Middle	Patient Middle Name	Middle name or, if middle name is unavailable, middle initial of the patient.	Patient Demographics	Middle Name	US Core Patient Profile	Patient.name.given	Lynn				
2270	Name--Suffix	Patient Suffix	Title that follows a patient's last name, such as a generation order or credential status (e.g., "MD," "Jr.").	Patient Demographics	Suffix	US Core Patient Profile	Patient.name.suffix					
2390	Name--Birth Surname	Patient Birth Surname	Maiden name of female patients who are or have been married.	Patient Demographics	Previous Name							
2280	Name--Alias	Patient Alias	Records an alternate name or "AKA" (also known as) used by the patient, if known.			US Core Patient Profile	Patient.name.use = anonymous					
2350	Addr Current--No & Street	Patient Street Address	The number and street address or the rural mailing address of the patient's current usual residence. This can be used to generate a follow-up inquiry and must correspond to other fields in the current address. If the patient has multiple tumors, the current address should be the same.	Patient Demographics	Current Address	US Core Patient Profile	Patient.address.line	111 Main Street				
2355	Addr Current--Supplemental	Patient Street Address Supplemental	This data item provides the ability to store additional address information such as the name of a place or facility, a nursing home, or the name of an apartment complex. This can be used to generate a follow-up inquiry and must correspond to other fields in the current address. If the patient has multiple tumors, the current address should be the same.	Patient Demographics	Current Address	US Core Patient Profile	Patient.address.line					
1810	Addr Current--City	Patient Address City	Name of city of the patient's current usual residence. If the patient has multiple tumors, the current city of residence should be the same for all tumors.	Patient Demographics	Current Address	US Core Patient Profile	Patient.address.city	Seattle		2.16.840.1.113883.6.245	U.S. Board on Geographic Names (USGS - GNIS)	2.16.840.1.114222.4.11.973
1820	Addr Current--State	Patient Address State	USPS abbreviation for the state, territory, commonwealth, U.S. possession, or CanadaPost abbreviation for the Canadian province /territory of the patient's current usual residence. If the patient has multiple tumors, the current state of residence should be the same for all tumors.	Patient Demographics	Current Address	US Core Patient Profile	Patient.address.state	WA		2.16.840.1.113883.6.92	FIPS 5-2 (State)	2.16.840.1.113883.3.88.12.80.1
1830	Addr Current—Postal Code	Patient Address Zip Code	Postal code for the address of the patient's current usual residence. If the patient has multiple tumors, the postal codes should be the same. For U.S. residents, use either the 5-digit or the extended 9-digit ZIP code. Blanks follow the 5-digit code. For Canadian residents, use the 6-character alphanumeric postal code. Blanks follow the 6-character code. When available, enter postal code for other countries.	Patient Demographics	Current Address	US Core Patient Profile	Patient.address.postalCode	98101		2.16.840.1.113883.6.231	USPostalCodes	2.16.840.1.113883.3.88.12.80.2
1832	Addr Current--Country	Patient Address Country	Country code for the address of patient's current usual residence. If the patient has multiple tumors, the current country of residence should be the same for all tumors.	Patient Demographics	Current Address	US Core Patient Profile	Patient.address.country	US		2.16.840.1.113883.3.88.12.80.63	Country	2.16.840.1.113883.3.88.12.80.63

2330	Addr at DX--No & Street	Patient Street Address	The number and street address or rural mailing address of the patient's residence at the time the reportable tumor was diagnosed.	Patient Demographics	Current Address or Previous Address	US Core Patient Profile	Patient.address.line					
2335	Addr at DX--Supplemental	Patient Street Address Supplemental	Provides the ability to store additional address information such as the name of a place or facility (for example a nursing home, apartment complex, jail or PO Box residential or other mailing address) at the time of diagnosis.	Patient Demographics	Current Address or Previous Address	US Core Patient Profile	Patient.address.line					
70	Addr at DX--City	Patient Address City	Name of the city in which the patient resides at the time the reportable tumor was diagnosed.	Patient Demographics	Current Address or Previous Address	US Core Patient Profile	Patient.address.city					
80	Addr at DX--State	Patient Address State	Identifies the patient's state or province of residence at the time of diagnosis as identified by the Reporting Source	Patient Demographics	Current Address or Previous Address	US Core Patient Profile	Patient.address.state					
100	Addr at DX—Postal Code	Patient Address Postal Code	Identifies the postal code of the patient's address at diagnosis.	Patient Demographics	Current Address or Previous Address	US Core Patient Profile	Patient.address.postalCode					
102	Addr at DX--Country	Patient Address Country	Country code for the address of the patient's residence at the time the reportable tumor is diagnosed.	Patient Demographics	Current Address or Previous Address	US Core Patient Profile	Patient.address.country					
90	County at Dx Reported	Patient Address County		Patient Demographics	Current Address or Previous Address							
		Patient Address Start Date	Address start date	Patient Demographics	Current Address or Previous Address?	US Core Patient Profile	Patient.address.period	June 23, 2005				
		Patient Address End Date	address end date	Patient Demographics	Current Address or Previous Address?	US Core Patient Profile	Patient.address.period	nullFlavor="NA"				
2360	Telephone	Patient Phone Number	Current telephone number with area code for the patient. Number is entered without dashes. Includes codes (in addition to valid telephone number).	Patient Demographics	Phone Number	US Core Patient Profile	Patient.telecom.value	(206)555-1313				
220	Sex	Patient sex	Code for the sex of the patient.	Patient Demographics	Birth Sex	US Core Patient Profile	Patient.extension:us-core-birthsex	F	Female	2.16.840.1.113883.5.1	AdministrativeGender	2.16.840.1.113883.1.11.1
240	Date of Birth	Patient date of birth	Date of birth of the patient.	Patient Demographics	Date of Birth	US Core Patient Profile	Patient.birthDate	February 20, 1960				
2300	Medical Record Number	Patient medical record number	Records medical record number used by the facility to identify the patient.			US Core Patient Profile	Patient.identifier.value	979746186				
	Patient identifier type	Patient Identifier Type	A coded type for the identifier that can be used to determine which identifier to use for a specific purpose.			US Core Patient Profile	Patient.identifier.type=MR	MR				
2320	Social Security Number	Patient Social Security Number	Records patient's social security number. The number is entered without dashes and without any letter suffix. This is not always identical to the Medicare claim number.			US Core Patient Profile	Patient.identifier.value	333-44-5555				
	Patient identifier type	Patient Identifier Type	A coded type for the identifier that can be used to determine which identifier to use for a specific purpose.			US Core Patient Profile	Patient.identifier.type=?					

2315	Medicare Beneficiary Identifier	Patient Medicare Beneficiary number	Congress passed the Medicare Access and CHIP Reauthorization ACT to remove Social Security Number (SSN) from Medicare ID card and replace the existing Medicare Health Insurance Claim Numbers with a Medicare Beneficiary Identifier (MBI). The MBI will be a randomly generated identifier that will not include a SSN or any personal identifiable information.			US Core Patient Profile	Patient.identifier.value					
	Patient identifier type	Patient Identifier Type	A coded type for the identifier that can be used to determine which identifier to use for a specific purpose.			US Core Patient Profile	Patient.identifier.type=SB	SB				
160	Race 1	Patient first reported race	A person's self-identification with one or more social groups. First reported race. (If the patient is multiracial, report all races using RACE 2 through RACE 5.)	Patient Demographics	Race	US Core Patient Profile	Patient.extension:us-core-race	2054-5	Black or African American	2.16.840.1.113883.6.238	Race & Ethnicity - CDC	2.16.840.1.113883.1.11.14914
161	Race 2	Patient second reported race	A person's self-identification with one or more social groups. Second reported race.	Patient Demographics	Race	US Core Patient Profile	Patient.extension:us-core-race	2106-3	White			
162	Race 3	Patient third reported race	A person's self-identification with one or more social groups. Third reported race.	Patient Demographics	Race	US Core Patient Profile						
163	Race 4	Patient fourth reported race	A person's self-identification with one or more social groups. Fourth reported race	Patient Demographics	Race	US Core Patient Profile						
164	Race 5	Patient fifth reported race	A person's self-identification with one or more social groups. Fifth reported race.	Patient Demographics	Race	US Core Patient Profile				2.16.840.1.113883.6.238	Race & Ethnicity - CDC	2.16.840.1.113883.1.11.14914
190	Spanish /Hispanic Origin	Patient Ethnicity	A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race	Patient Demographics	Ethnicity	US Core Patient Profile	Patient.extension:us-core-ethnicity	2186-5	Not Hispanic or Latino	2.16.840.1.113883.6.238	Race & Ethnicity - CDC	2.16.840.1.114222.4.11.837
252	Birthplace--State	Patient State of Birth	USPS abbreviation for the state, territory or U.S. possession.					PA		2.16.840.1.113883.6.92	FIPS 5-2 (State)	2.16.840.1.113883.3.88.12.80.1
254	Birthplace--Country	Patient Country of Birth	The country in which the patient was born.					US		2.16.840.1.113883.3.88.12.80.63	Country	2.16.840.1.113883.3.88.12.80.63
150	Marital Status at DX	Patient Marital Status	Code for the patient's marital status. (removed the NAACCR requirement that it's status at time of diagnosis)			US Core Patient Profile	Patient.maritalStatus	M	Married	2.16.840.1.113883.5.2	MaritalStatus	2.16.840.1.113883.1.11.12212
1760	Vital Status	Vital Status	Vital status (dead or alive) of the patient as of the date entered in Date of Last Contact [1750]. If the patient has multiple tumors, vital status should be the same for all tumors.			Patient	Patient.deceasedBoolean	false				
	Date of First Contact	Date of Patient First Visit	Date of the patient's first visit with the reporting provider			eICR Encounter	period.start					
1750	Date of Last Contact	Date of Death	Date of last contact with the patient, or date of death. If the patient has multiple tumors, Date of Last Contact should be the same for all tumors.				Patient.deceasedDateTime					
		Patient Smoking Status	Current smoking status	Smoking Status	Smoking Status	US Core Smoking Status Observation Profile	Observation.valueCodeableConcept.code	8517006	Former smoker	2.16.840.1.113883.6.96	SNOMED CT	2.16.840.1.113883.11.20.9.38

		Patient Smoking Status Date	Date patient's smoking status was recorded			US Core Smoking Status Observation Profile	Observation.effective[x]	<date of the encounter>				
Provider Information												
2465	NPI--Physician--Managing	Managing Provider NPI	The NPI (National Provider Identifier) code that identifies the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?	If Care Team Members. then consider submitting new element(s)	USCorePractitionerProfile	Practitioner.identifier:NPI	1234567893		2.16.840.1.113883.4.6	National Provider Identifier	
		Managing Provider Name	The full name of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?		USCorePractitionerProfile	Practitioner.name.text	Alex Karev, MD				
		Managing Provider Last Name	The last name of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?		USCorePractitionerProfile	Practitioner.name.family	Karev				
		Managing Provider First Name	The first name of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?		USCorePractitionerProfile	Practitioner.name.given	Alex				
		Managing Provider Specialty	The medical specialty of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?				207RX0202X	Medical Oncology	2.16.840.1.113883.6.101	Healthcare Provider Taxonomy (HIPAA)	2.16.840.1.114222.4.11.1066
		Managing Provider Street Address	The street address of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?		USCorePractitionerProfile	Practitioner.address	999 Ellis Way				
		Managing Provider Address City	The city of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?		USCorePractitionerProfile	Practitioner.address	Seattle		2.16.840.1.113883.6.245	U.S. Board on Geographic Names (USGS - GNIS)	2.16.840.1.114222.4.11.973
		Managing Provider Address State	the State of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?		USCorePractitionerProfile	Practitioner.address	WA		2.16.840.1.113883.6.92	FIPS 5-2 (State)	2.16.840.1.113883.3.88.12.80.1
		Managing Provider Address Postal Code	The postal code of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?		USCorePractitionerProfile	Practitioner.address	98101		2.16.840.1.113883.6.231	USPostalCodes	2.16.840.1.113883.3.88.12.80.2
		Managing Provider Address Country	The country of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?		USCorePractitionerProfile	Practitioner.address	US		2.16.840.1.113883.3.88.12.80.63	Country	2.16.840.1.113883.3.88.12.80.63

		Managing Provider Email Address	The email of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?				Akarev@GraceOnc.com				
		Managing Provider Telephone Number	The telephone number of the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.	Provenance and/or Care Team Members?				(206) 555-3921				
2475	NPI--Physician--Follow-Up	Primary Care Physician NPI	The NPI (National Provider Identifier) code for the physician currently responsible for the patient's medical care.	Provenance and/or Care Team Members?								
2495	NPI--Physician 3	Radiation Oncologist NPI	The NPI (National Provider Identifier) code for another physician involved in the care of the patient, e.g., radiation oncologist	Provenance and/or Care Team Members?								
2505	NPI--Physician 4	Medical Oncologist NPI	The NPI (National Provider Identifier) code for another physician involved in the care of the patient, e.g., medical oncologist	Provenance and/or Care Team Members?								
	NPI--Inst Referred To	Referred To Provider NPI	The NPI (National Provider Identifier) code that identifies the facility to which the patient was referred for further care.	Provenance and/or Care Team Members?								
545	NPI--Reporting Facility	Reporting Facility NPI	The NPI (National Provider Identifier) code for the facility submitting the data in the record.	Provenance	Author Organization?			2987654326		2.16.840.1.113883.4.6	National Provider Identifier	
		Reporting Facility Name	Name for the facility submitting the data in the record.					Seattle Grace Oncology Clinic				
		Reporting Facility Street Address	Street Address for the facility submitting the data in the record.					999 Ellis Way				
		Reporting Facility Address City	City for the facility submitting the data in the record.					Seattle		2.16.840.1.113883.6.245	U.S. Board on Geographic Names (USGS - GNIS)	2.16.840.1.114222.4.11.973
		Reporting Facility Address State	State for the facility submitting the data in the record.					WA		2.16.840.1.113883.6.92	FIPS 5-2 (State)	2.16.840.1.113883.3.88.12.80.1
		Reporting Facility Address Postal Code	Postal Code for the facility submitting the data in the record.					98101		2.16.840.1.113883.6.231	USPostalCodes	2.16.840.1.113883.3.88.12.80.2
		Reporting Facility Address Country	Country for the facility submitting the data in the record.					US		2.16.840.1.113883.3.88.12.80.63	Country	2.16.840.1.113883.3.88.12.80.63
		Reporting Facility Phone Number	Phone # for the facility submitting the data in the record.					(206) 555-3900				
2415	NPI--INST REFERRED FROM	Referring Facility NPI	The NPI (National Provider Identifier) code that identifies the facility that referred the patient to the reporting facility.					1590101014		2.16.840.1.113883.4.6	National Provider Identifier	
2410	INSTITUTION REFERRED FROM	Referring Facility Name	Identifies the facility that referred the patient to the reporting facility.					Seattle Grace Hospital				

		Provider Role	The role of the provider, which would apply to each of the individual provider types (above)	Provenance and/or Care Team Members?								
2508	EHR Vendor Name	EHR Vendor Name	The name of the software vendor for the EHR that created the report	Provenance?				Epic				
2508	EHR Software Name	EHR Software Name	The name of the software that created the report	Provenance?				Beacon				
2508	EHR Software Version	EHR Software Version	The version number of the software that created the report	Provenance?				V 1.4				
Encounter Information												
		Encounter period	The start and end times of the encounter.			US Core Encounter Profile	Encounter. period					
		Reason for visit	Reason the encounter takes place, expressed as a code. (Reason for Visit) **Need to review with WG**									
		Encounter primary diagnosis	Reason the encounter takes place, as specified using information from another resource. For admissions, this is the admission diagnosis. The indication will typically be a Condition (with other resources referenced in the evidence. detail), or a Procedure. "For systems that need to know which was the primary diagnosis, these will be marked with the standard extension primaryDiagnosis (which is a sequence value rather than a flag, 1 = primary diagnosis)." (Encounter primary diagnosis) Need to review with WG									
		Classification of Pt, Encounter	inpatient | outpatient | ambulatory | emergency +.			US Core Encounter Profile	Encounter.class					
		Encounter subject	The patient or group present at the encounter.			US Core Encounter Profile	Encounter. subject					
		Encounter Identifier	Identifier(s) by which this encounter is known.			US Core Encounter Profile	Encounter. identifier.value					
		Encounter participant	The list of people responsible for providing the service.			US Core Encounter Profile	Encounter. participant					
		Encounter participant type	Role of participant in encounter.			US Core Encounter Profile	Encounter. participant.type					
		Primary participant responsible for encounter	Encounter principal performer of service.			US Core Encounter Profile	Encounter. participant. type=PPRF					
		Participant overseeing the encounter	Participant overseeing the encounter			US Core Encounter Profile	Encounter. participant. type=ATND					
		Encounter participant individual	Persons involved in the encounter other than the patient. Reference (US Core Practitioner Profile)			US Core Encounter Profile	Encounter. participant. individual					
		Encounter primary performer NPI	NPI of encounter principal performer.			US Core Encounter Profile	Encounter. participant. individual. Practitioner. identifier:NPI					
		Encounter primary performer name	Name of encounter principal performer.			US Core Encounter Profile	Encounter. participant. individual. Practitioner. name					

		Encounter primary performer professional role	Professional role of encounter principal performer.			?	Encounter. participant. individual. PractitionerRole.code					
		Encounter location address	The location where the encounter takes place.			US Core Encounter Profile	Encounter. location. location. address					
		Encounter location NPI	The NPI Number for the facility where the encounter takes place: **For WG discussion: Healthcare Surveys did not include this data element. Is there interest in adding it?**									
630	Primary Payer at DX	Primary payer type	The type of coverage: social program, medical plan, accident coverage (workers compensation, auto), group health or payment by an individual or organization.			US Core Encounter Profile	Encounter. account. coverage.type		BC Managed Care or equivalent			
Cancer Diagnosis Information												
		Does not map, but might be similar concept in FHIR that we should consider whether needed	CDA Data Element: statusCode (for cancer diagnosis observation)	Problems	Problems	Document Reference or Diagnostic Report or Condition		active				
390	Date of Diagnosis	Cancer Date of Diagnosis	Date of initial diagnosis by a recognized medical practitioner	Problems	Problems	Document Reference or Diagnostic Report or Condition		January 26, 2018				
	Doesn't map to a SINGLE item	Cancer Diagnosis Code	Code for the cancer diagnosis being reported	Problems	Problems	Condition		408643008	Infiltrating duct carcinoma of breast (disorder)	2.16.840.1.113883.6.96	SNOMED CT	Needs to be developed
	Doesn't map to a SINGLE item	Cancer Diagnosis Code	Code for the cancer diagnosis being reported					C50.411	Malignant neoplasm of upper-outer quadrant of right female breast	2.16.840.1.113883.6.90	ICD-10-CM	Have list of values in emarc; will need to publish as value set
522	Histologic Type ICD-O-3	Cancer Histologic Type	The histologic type of the tumor	Problems	Problems	Condition		8500/3 OR 8500	Infiltrating duct carcinoma, NOS	2.16.840.1.113883.6.43.1	ICD-O-3	Is there a way for us to create a VS to restrict these to only the Morphology codes?
	Histologic Type ICD-O-3	Cancer Histologic Type						82711006	Infiltrating duct carcinoma	2.16.840.1.113883.6.96	SNOMED CT	2.16.840.1.114222.4.11.7256
523	Behavior Code ICD-O-3	Cancer Behavior	The behavior of the tumor (morphology)	Problems	Problems	Condition		3	Malignant, primary site	2.16.840.1.113883.3.520.3.14	NAACCR Behavior Code	2.16.840.1.113883.3.520.4.14
3843	Grade Clinical	Cancer Clinical Grade	The clinical grade of a solid primary tumor before any treatment (surgical resection or initiation of any treatment including neoadjuvant).	Problems	Problems	Condition		1	Grade I	2.16.840.1.113883.3.520.3.15	NAACCR Grade	2.16.840.1.113883.3.520.4.15
3844	Grade Pathological	Cancer Pathological Grade	The pathological grade of a solid primary tumor that has been resected and for which no neoadjuvant therapy was administered	Problems	Problems	Condition		1	Grade I	TBD	TBD	TBD
3845	Grade Post Therapy Path (yp)	Cancer Post Treatment Grade	The post-treatment grade of a solid primary tumor that has been resected following neoadjuvant therapy	Problems	Problems	Condition		1	Grade I	TBD	TBD	TBD

490	Diagnostic Confirmation ICD-O-3	Cancer Diagnostic Confirmation Method	Code for the best method of diagnostic confirmation of the cancer being reported at any time in the patient's history.	Problems	Problems	Condition		1	Positive histology	2.16.840.1.113883.3.520.3.3	NAACCR Diagnostic Confirmation	2.16.840.1.113883.3.520.4.3
400	Primary Site	Cancer Primary Site	Code for the primary site of the tumor being reported	Problems	Problems	Condition		C50.4	Upper-outer quadrant of breast	2.16.840.1.113883.6.43.1	ICD-O-3	Is there a way for us to create a VS to restrict these to only the Topography codes?
	Primary Site	Cancer Primary Site						110496004	Upper outer quadrant of right breast	2.16.840.1.113883.6.96	SNOMED CT	2.16.840.1.113883.3.88.12.3221.8.9
	Primary Site	Cancer Primary Site						C50.411	Malignant neoplasm of upper-outer quadrant of right female breast	2.16.840.1.113883.6.90	ICD-10-CM	
410	Laterality	Cancer Laterality	The side of a paired organ, or the side of the body on which the reportable tumor originated	Problems		Condition		24028007	Right (qualifier value)	2.16.840.1.113883.6.96	SNOMED CT	2.16.840.1.113883.3.520.4.22
1060	TNM Edition Number	Cancer TNM Stage Edition /Version Number	The edition of the AJCC manual used to stage the cancer	Problems		Condition						
	No mapping, but can be used to determine stage at diagnosis	Cancer Date TNM Clinical Stage Assigned	Date/time TNM clinical stage information was assigned	Problems		Condition		February 11, 2018				
1004	AJCC TNM Clin Stage Group	Cancer TNM Clinical Stage Group	Detailed site-specific codes for the clinical stage group as defined by AJCC	Problems		Condition		IIIA OR 3A		2.16.840.1.113883.3.520.3.18	TNM 8. Edition	2.16.840.1.113883.3.520.4.30
980	TNM Clin Descriptor	Cancer TNM Clinical Descriptor	Identifies the AJCC clinical stage (prefix /suffix) descriptor as recorded by the physician. AJCC stage descriptors identify special cases that need separate data analysis. The descriptors are adjuncts to and do not change the stage group.	Problems		Condition		0	None	2.16.840.1.113883.15.6	TNM 7. Edition	2.16.840.1.113883.3.520.4.10
1001	AJCC TNM Clin T	Cancer TNM Clinical Tumor	Detailed site-specific codes for the clinical tumor (T) as defined by AJCC	Problems		Condition		cT2 or c2		2.16.840.1.113883.3.520.3.18	TNM 8. Edition	2.16.840.1.113883.3.520.4.32
1002	AJCC TNM Clin N	Cancer TNM Clinical Nodes	Detailed site-specific codes for the clinical nodes (N) as defined by AJCC	Problems		Condition		cN2 OR c2		2.16.840.1.113883.3.520.3.18	TNM 8. Edition	2.16.840.1.113883.3.520.4.33
1003	AJCC TNM Clin M	Cancer TNM Clinical Metastases	Detailed site-specific codes for the clinical metastases (M) as defined by AJCC	Problems		Condition		cM0 OR c0		2.16.840.1.113883.3.520.3.18	TNM 8. Edition	2.16.840.1.113883.3.520.4.34
	No mapping, but can be used to determine stage at diagnosis	Cancer Date TNM Pathological Stage Assigned	Date/time TNM pathological stage information was assigned	Problems		Condition		February 11, 2018				
1014	AJCC TNM Path Stage Group	Cancer TNM Pathological Stage Group	Detailed site-specific codes for the pathologic stage group as defined by AJCC	Problems		Condition		IIIA OR 3A		2.16.840.1.113883.3.520.3.18	TNM 8. Edition	2.16.840.1.113883.3.520.4.35

920	TNM Path Descriptor	Cancer TNM Pathological Descriptor	Identified the AJCC pathologic stage (prefix /suffix) descriptor as recorded by the physician. AJCC stage descriptors identify special cases that need separate data analysis. The descriptors are adjuncts to and do not change the stage group.	Problems		Condition		0	None	2.16.840.1.113883.15.6	TNM 7. Edition	2.16.840.1.113883.3.520.4.21
1011	AJCC TNM Path T	Cancer TNM Pathological Tumor	Detailed site-specific codes for the pathologic tumor (T) as defined by AJCC	Problems		Condition		pT2 OR p2		2.16.840.1.113883.3.520.3.18	TNM 8. Edition	2.16.840.1.113883.3.520.4.37
1012	AJCC TNM Path N	Cancer TNM Pathological Nodes	Detailed site-specific codes for the pathologic nodes (N) as defined by AJCC	Problems		Condition		pN2 OR p2		2.16.840.1.113883.3.520.3.18	TNM 8. Edition	2.16.840.1.113883.3.520.4.38
1013	AJCC TNM Path M	Cancer TNM Pathological Metastases	Detailed site-specific codes for the pathologic metastases (M) as defined by AJCC	Problems		Condition		cM0 OR c0		2.16.840.1.113883.3.520.3.18	TNM 8. Edition	2.16.840.1.113883.3.520.4.39
Medications (Treatment)												
	Does not map, but might be similar concept in FHIR that we need to use.	Medication Status	Indicates whether the medication was prescribed, administered, etc. (Discuss with the WG--what do we want to capture for systemic therapy/meds?)	Medications				EVN		2.16.840.1.113883.5.1001	ActMood	2.16.840.1.113883.11.20.9.18
1220 1230 1240 1250	RX Date Chemo RX Date Hormone RX Date BRM RX Date Other	Date medication prescribed	Date medication was prescribed	Medications								
1390 1400 1410 1420	RX Summ--Chemo RX Summ--Hormone RX Summ--BRM RX Summ--Other	Medication prescribed code	Code (with associated name) for the medication that was prescribed	Medications	Medications			1720960	26.3 ML gemcitabine 38 MG /ML Injection	2.16.840.1.113883.6.88	RxNorm	2.16.840.1.113762.1.4.1010.4
	Does not map; ask WG whether to keep	Medication prescribed dose	Dose for the medication that was prescribed					2225				
	Does not map; ask WG whether to keep	Medication prescribed dose units	Units of measure for the medication that was prescribed					mg		2.16.840.1.113883.6.8	UCUM	2.16.840.1.113883.1.11.12839
	RX Date Chemo RX Date Hormone RX Date BRM RX Date Other	Date medication administered	A specific date/time or interval of time during which the medication administration took place.									
	RX Summ--Chemo RX Summ--Hormone RX Summ--BRM RX Summ--Other	Medication administered code	Identifies the code (with associated name) for the medication that was administered.									
	Does not map; ask WG whether to keep	Medication administered dose	Dose for the medication that was administered									

	Does not map; ask WG whether to keep	Medication administered dose units	Units of measure for the medication that was administered									
		Medication Reason	We need a way to link medications to the correct cancer diagnosis when there is more than one cancer diagnosis in the same report. Note: will there multiple cancer diagnoses in the same FHIR bundle, or would they each be sent in a separate bundle, in which case this linkage is not needed? (A code indicating why the medication was given.)									
Problems												
		Patient Problem Onset Date	Date of onset of the patient's preexisting medical conditions, factors influencing health status, and/or complications for the treatment of this cancer	Problems				May 12, 1990				
3780, 3782, 3784, 3786, 3788, 3790, 3792, 3794, 3796, 3798	Secondary Diagnosis 1-10	Patient Problem Code	Records the patient's preexisting medical conditions, factors influencing health status, and/or complications for the treatment of this cancer.	Problems	Problems			44054006	Diabetes mellitus type 2	2.16.840.1.113883.6.96	SNOMED CT	2.16.840.1.113883.3.88.12.3221.7.4
3780, 3782, 3784, 3786, 3788, 3790, 3792, 3794, 3796, 3798	Secondary Diagnosis 1-10	Patient Problem Code						E11.9	Type 2 diabetes mellitus without complications	2.16.840.1.113883.6.90	ICD-10-CM	
Procedures												
1290670	RX Summ--Surg Prim Site RX Hosp--Surg Prim Site	Procedure Code	Procedure to the primary site performed as part of the first course of treatment.	Procedures	Procedures			442963006	Percutaneous needle biopsy of breast using ultrasound guidance	2.16.840.1.113883.6.96	SNOMED CT	Is there a value set for procedures? If not, should /can we create one?
1290670	RX Summ--Surg Prim Site RX Hosp--Surg Prim Site	Procedure Code		Procedures	Procedures			19083	Biopsy, breast, with placement of breast localization device(s) (e.g., clip, metallic pellet), when performed, and imaging of the biopsy specimen, when performed, percutaneous; first lesion, including ultrasound guidance	2.16.840.1.113883.6.12	CPT-4	We can't publish a CPT value set.
1290670	RX Summ--Surg Prim Site RX Hosp--Surg Prim Site	Procedure Code		Procedures	Procedures			0HBT3ZX	Excision of Right Breast, Percutaneous Approach, Diagnostic	2.16.840.1.113883.6.4	ICD10 PCS	See item in TFS for value set

1200 3170	RX Date Surg RX Date Mst Defn Srg	Procedure Performed Date	Date/time of the procedure to the primary site performed as part of the first course of treatment.	Procedures				January 26, 2018				
		Procedure Performed Facility	Facility (NPI/Name) where the procedure was performed									
		Procedure Reason	We need a way to link procedures to the correct cancer diagnosis when there is more than one cancer diagnosis in the same report. Note: will there multiple cancer diagnoses in the same FHIR bundle, or would they each be sent in a separate bundle, in which case this linkage is not needed?									
1506	Phase 1 Radiation Treatment Modality	Radiation Code	Identifies the radiation modality administered during the first phase of radiation treatment delivered as part of the first course of treatment	Procedures?	Procedures?			77412	Radiation treatment delivery, 1 MeV; complex	2.16.840.1.113883.6.14	HCPCS	2.16.840.1.113883.3.520.4.23; but we can't publish the CPT codes in this value set.
1506	Phase 1 Radiation Treatment Modality	Radiation Code						448385000	Megavoltage radiation therapy using photons	2.16.840.1.113883.6.96	SNOMED CT	2.16.840.1.113883.3.520.4.23
1506	Phase 1 Radiation Treatment Modality	Radiation Code						DM011ZZ	Beam Radiation of Right Breast using Photons 1 - 10 MeV	2.16.840.1.113883.6.4	ICD10 PCS	2.16.840.1.113883.3.520.4.23
1210	RX Date Radiation	Radiation Administered Start Date	Date on which radiation therapy began at any facility that is part of the first course of treatment.	Procedures?				09/14/2018				
		Radiation Reason	We need a way to link radiation procedures to the correct cancer diagnosis when there is more than one cancer diagnosis in the same report. Note: will there multiple cancer diagnoses in the same FHIR bundle, or would they each be sent in a separate bundle, in which case this linkage is not needed?									
Lab Results												
		Laboratory Test /Panel Code	The test (or panel of tests) that was performed relevant to the cancer diagnosis . A LOINC SHALL be used if the concept is present in LOINC.	Laboratory	Tests			10480-2	Estrogen+ Progesterone receptor Ag [Presence] in Tissue by Immune stain	2.16.840.1.113883.6.1	LOINC	Value set to be developed to restrict to cancer-related (or can we do a "blacklist" approach--which tests are NOT wanted)
		Laboratory Test Result Status	The status of the result value					completed		2.16.840.1.113883.5.14	ActStatus	2.16.840.1.113883.11.20.9.39
		Laboratory Test Performed Date	Date test was performed	Laboratory				January 26, 2018				
		Laboratory Result Value	The Laboratory result value.	Laboratory	Values /Results			Positive		2.16.840.1.113883.6.96	SNOMED CT	

		Laboratory Result Units of Measure	Units of measure for the laboratory result value.	Laboratory	Values /Results					2.16.840.1.113883.6.8	UCUM	2.16.840.1.113883.13.11.12839
Employment History												
		Patient Industry Period	Date patient's industry code was recorded					April 1985-present				
272	Census Ind Code 2010 CDC	Patient Industry Code	Code for the patient's usual industry, using U. S. Census Bureau codes and NIOSH non-paid worker codes					6570	Motion pictures and video industries	2.16.840.1.114222.4.5.315	Industry CDC Census 2010	2.16.840.1.114222.4.11.7187
		Patient Occupation Period	Date patient's occupation code was recorded					April 1985-present				
282	Census Occ Code 2010 CDC	Patient Occupation Code	Code for the patient's usual occupation, using U.S. Census Bureau codes and NIOSH non-paid worker codes					2700	Actors	2.16.840.1.114222.4.5.314	Occupation CDC Census 2010	2.16.840.1.114222.4.11.7186
Vital Signs												
		Patient Height Code	Patient Height code	Vital Signs	Body height			8302-2	Height	2.16.840.1.113883.6.1	LOINC	2.16.840.1.113883.13.3.88.12.80.62
		Patient Height Recorded Date	Date patient's height was recorded					<date of the encounter>				
		Patient Height Value	Patient Height value	Vital Signs	Body height			162.5				
		Patient Height Units	Patient Height units	Vital Signs	Body height			cm		2.16.840.1.113883.6.8	UCUM	2.16.840.1.113883.13.11.12839
		Patient Weight Code	Patient Weight code	Vital Signs	Body weight			3141-9 or 29463-7	Weight Measured or Weight	2.16.840.1.113883.6.1	LOINC	2.16.840.1.113883.13.3.88.12.80.62
		Patient Weight Recorded Date	Date patient's weight was recorded					<date of the encounter>				
		Patient Weight Value	Patient Weight value	Vital Signs	Body weight			72.5				
		Patient Weight Units	Patient Weight units	Vital Signs	Body weight			kg		2.16.840.1.113883.6.8	UCUM	2.16.840.1.113883.13.11.12839
Clinical Notes/Text Fields												
	TBD	Consultation Note Content	**To be discussed with WG--do cancer registries want this? Are they allowed to receive it?**	Clinical Notes	Consultation Note							
	TBD	Discharge Summary Note Content	**To be discussed with WG--do cancer registries want this? Are they allowed to receive it?**	Clinical Notes	Discharge Summary Note							
2520	Text--DX Proc--PE	History & Physical Content	**To be discussed with WG--do cancer registries want this? Are they allowed to receive it?**	Clinical Notes	History & Physical							
2530	Text--DX Proc--X-ray/Scan	Imaging Narrative Content	**To be discussed with WG--do cancer registries want this? Are they allowed to receive it?**	Clinical Notes	Imaging Narrative							
2550	Text--DX Proc--Lab Tests	Laboratory Report Narrative Content	**To be discussed with WG--do cancer registries want this? Are they allowed to receive it?**	Clinical Notes	Laboratory Report Narrative							
2570	Text--DX Proc--Path	Pathology Report Narrative Content	**To be discussed with WG--do cancer registries want this? Are they allowed to receive it?**	Clinical Notes	Pathology Report Narrative							
2560	Text--DX Proc--Op	Procedure Note Content	**To be discussed with WG--do cancer registries want this? Are they allowed to receive it?**	Clinical Notes	Procedure Note							

	TBD	Progress Note Content	**To be discussed with WG--do cancer registries want this? Are they allowed to receive it?**	Clinical Notes	Progress Note							
2630	RX Text--Radiation Other	Radiation Therapy Treatment Summary Content	Text area for manual documentation of information regarding treatment of the tumor being reported with beam radiation. To be discussed with WG--do cancer registries want this? Are they allowed to receive it?	Clinical Notes	**Note: Flag for candidate for submission to ONDEC (new data element)?: Radiation Therapy Treatment Summary**			Patient received 5 MeV radiation treatment				

Table 3: Cancer Reporting Data Elements

Policy Considerations

Policy considerations for the use case to be implemented in the real-world include:

- MedMorph will use existing frameworks (e.g., FHIR APIs) for the exchange of data.
- When there is a third party, a data use or business use/associate agreement may be needed (e.g., APHL).
- Public Health Agencies may have state-specific restrictions on collecting protected classes of data (e.g., AIDS status, mental health status, SUD/OUD).
    - If the patient gives consent for sharing of AIDs, mental health, etc. data the burden would be on the sending system.
    - For research use cases, there must be consent before the data is sent.
- For jurisdictional restrictions on data that can not be collected, the MedMorph Reference Architecture will make provisions for defining actions (e.g., redaction, filtering, removal, validation) before submission. The actions could be triggered based on the content of specific data elements.
    - The MedMorph Reference Architecture will do an additional validation check on the data before the data leaves the healthcare organization. This is important in cases of a healthcare organization reporting to multiple jurisdictions.
- What if more data is sent that what is requested?
    - Registries may have restrictions on collecting certain information. For example, cancer registries collect comorbidity information, but some of them are restricted from collecting information about AIDS or mental health conditions as a comorbidity
    - This should be handled by policy and processes around the data received.
    - The data generator should be clear on what data is being requested and the data provided should only be the data requested.
    - The Reference Architecture IG will ask for feedback during the ballot process on if the MedMorph Reference Architecture should define an acknowledgment mechanism for notifications when additional data is received.

Non-Technical Considerations

Non-technical considerations for the use case to be implemented in the real-world include:

- On boarding of EHRs and or tracking systems
- The use and or restrictions of FHIR between trading entities
- Should we use specific histology/morphology codes, such as those used in pathology reports?
- Will we consider reporting guidelines, such as certain data content that should be reported under certain specific circumstances (e.g., based on cancer type, stage, treatment?
- Registries will capture what they are required to capture by state laws and standards setters but research use cases might want to capture complications, etc related to cancer.

Appendices

Related Use Cases and Links

- North American Association of Central Cancer Registries (NAACCR): https://www.naaccr.org/
- NAACCR Data Standards and Data Dictionary: https://www.naaccr.org/data-standards-data-dictionary/

References to Appropriate Documentation

- USCDI: https://www.healthit.gov/isa/us-core-data-interoperability-uscdi

Terms and Definitions

- **Central Cancer Registry**[3]: an information system designed for the collection, storage, and management of data on persons with cancer. Registries play a critical role in cancer surveillance, which tells us where we are in the efforts to reduce the cancer burden. Surveillance data may also serve as a foundation for cancer research and are used to plan and evaluate cancer prevention and control interventions.
- **Electronic Health Record (EHR)**[4]: a real-time, patient-centered record that makes information available instantly and securely to authorized users. While an EHR contains the medical and treatment histories of patients, an EHR system is built to go beyond standard clinical data collected in a provider's provision of care location and can be inclusive of a broader view of a patient's care. EHRs are a vital part of health IT and can:
    - Contain a patient's medical history, diagnoses, medications, treatment plans, immunization dates, allergies, radiology images, and laboratory and test results
    - Allow access to evidence-based tools that providers can use to make decisions about a patient's care
    - Automate and streamline provider workflow
- **Use Case:** Document used to capture user (actor) point of view while describing functional requirements of the system. They describe the step by step process a user goes through to complete that goal using a software system. A Use Case is a description of the ways an end-user wants to "use" a system. Use Cases capture ways the user and system can interact that result in the user achieving the goal. (adapted from https://www.visual-paradigm.com/)
- **User Story**: A User Story is a note that captures what a user does or needs to do as part of his/her work. Each User Story consists of a short description written from user's point of view, with natural language. (adapted from https://www.visual-paradigm.com/)

Parking Lot Topics for Technical Workgroups

- Workflows or Reference Architecture:
    - Include querying data from big data platforms? What permissions are needed?
- Workflows:
    - Triggers: reason for visit/encounter, diagnosis, problem list, pathology report
- Reference Architecture:
    - Keep track of submissions to registry so that an initial report isn't resubmitted over and over?

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[1] Menck, H., Gress, D. and Griffin, A., 2011. *Cancer Registry Management Principles and Practices for Hospitals and Central Registries*. 3rd ed. Dubuque, IA: Kendall Hunt. ISBN: 978-0-7575-6900-5

[2] Adapted from https://www.healthit.gov/faq/what-electronic-health-record-ehr

[3] Adapted from: https://seer.cancer.gov/registries/cancer_registry/index.html

[4] Adapted from: https://www.healthit.gov/faq/what-electronic-health-record-ehr