

**National Program of Cancer Registries –
Modeling Electronic Reporting Project**

**Central Cancer Registry Strategic
Assessment and Modeling Session**

Requirements Findings

Atlanta, GA

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CDC/DCPC/NPCR

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1 BACKGROUND

The Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries – Modeling Electronic Reporting Project (NPCR-MERP) is a collaborative effort to position the cancer surveillance community to take advantage of the electronic medical record (EMR) for cancer surveillance through automated capture of electronically available data. This will be accomplished by developing consensus-based recommendations and guidelines, reflected in models to represent the flow of data through all levels of the cancer surveillance system. The model will include flow processes from the hospital's EMR (which includes multiple database systems) and other cancer registry data sources (such as private pathology labs) to the hospital cancer registry; from the hospital cancer registry to the state central cancer registry; and from the state central cancer registry to the national programs [CDC National Program of Cancer Registries (NPCR), National Cancer Institute (NCI) Surveillance, Epidemiology, and End results (SEER), American College of Surgeons (ACoS) Commission on Cancer (CoC) and North American Association of Central Cancer Registries, Inc. (NAACCR)].

The purpose of NPCR-MERP is to construct a comprehensive model that can enable NPCR to demonstrate the potential of electronic cancer registry reporting to their grantees and partners to:

- Reduce cancer burden in the U.S. population;
- Identify new capabilities offered by electronic capture of patient information;
- Incorporate national standards;
- Identify ways to improve completeness, timeliness and quality of data;
- Identify opportunities to automate manual processes for data capture;
- Present models in multiple levels of granularity and specificity;
- Reduce costs for registries and data providers significantly over time;
- Reflect current industry best practices.

Phase I of the project was a collaboration effort with the Virginia Commonwealth University Hospital System (VCUHS), the Virginia Cancer Registry (VCR), the NCI SEER program, the CDC NPCR, Northrop Grumman IT, and Scientific Technologies Corporation to develop a proposed “straw man” model that would be used to begin discussions with the broader cancer surveillance community. Phase II is commencing with a series of focused Strategic Assessment and Modeling Sessions (SAMS) aimed at gaining national input on the modeling activity of the NPCR-MERP Team. The idea is to develop the electronic reporting component of a comprehensive national consensus model that outlines best practices, guidelines, and recommendations for the introduction of electronic data exchange within cancer surveillance.

The first Central Cancer Registry (CCR) Strategic Assessment and Modeling Session (SAMS) included program managers from several NPCR funded states and focused on gathering a broad understanding of the CCR business and barriers to electronic reporting. Objectives for the first CCR SAMS: define CCR core functions with the focus on electronic reporting; identify best and worse case scenarios; identify barriers to electronic reporting; identify opportunities for immediate impact; and, review diagrams.

2 SAMS OBJECTIVES

This is the second CCR SAMS session designed to build on the work completed in the first SAMS and includes a wider variety of CCR experts such as cancer registrars, epidemiologist/statisticians, data managers/IT, program managers, central registry software vendors, standard setters, and others to provide expertise on cancer registration and electronic reporting. During the SAMS participants provided detailed feedback on ideal practices related to specific CCR functions in an ideal electronic reporting infrastructure.

2.1 Objectives

- 2.1.1 To define a comprehensive list of functions that would benefit from electronic manipulation of registry data. For each core function determine how data is retrieved, transmitted, stored, analyzed, utilized, etc.
Note: Special emphasis will be on the transmission of data from hospital cancer registry and other external data sources into the central cancer registry.
- 2.1.2 To define and/or refine CCR-related diagrams that expressed CCR entities, processes, data flows, transmission protocols, and standards.
- 2.1.3 To establish a representative audience that can be added to the existing CCR workgroup, to provide continued feedback and guidance on the CCR component of the NPCR-MERP Guidelines, Recommendations, and Best Practices in cancer registry electronic reporting.

3 SAMS AGENDA

3.1 Day One

Opening comments and introductions
Project briefing
SAMS orientation
Project definition
Brainstorm barriers/challenges and enablements
Closing comments

3.2 Day Two

Review prior work
CCR core functions
Process mapping orientation
High-level map of CCR core functions
Prioritize CCR core functions
Detailed map of as-is model for “Receive event reports”
Improvement opportunities
Debriefing

3.3 Day Three

Review detailed as-is model and discussed boundaries of case finding
Review high-level as-is model (see Appendix A for the UML diagram)
Identify additional opportunities
Develop to-be model for “Receive event reports”
Develop decision tables for “Receive event reports and accept event reports”
Develop business use case
Debriefing and closing

4 PROJECT DEFINITION

This SAMS contributes to developing a blueprint for electronic reporting of cancer data that will:

- Identify priorities to make better use of cancer surveillance resources;
- Provide guidance, best practices and a series of resources for development of standards-based systems for cancer registration;
- Enable the reduction of the number of manual processes;
- Enable better use of the Certified Tumor Registrars’ (CTRs) time.

Participants revised the project definition from, “Develop a blueprint for electronic reporting of cancer data” to “Develop a blueprint for electronic reporting and automated transmission and automated processing of cancer data.”

Action item: wordsmith the electronic reporting definition. There was extensive discussion on the meaning of ‘electronic reporting’. Does it include exchanging data on the web? What is human interface? Definitions discussed:

- A machine readable format can be exchanged by one system and consumed by another system. (definition in glossary)
- Automated transmission of data between 2 or more parties.
- Communication between 2 systems.
- Machine to machine communication of data.
- Transfer of information from one computer-based system to one or more other computer-based systems where the primary operator is not human.
- Automated, unattended (by human) transmission of data between 2 or more parties.

5 BARRIERS/CHALLENGES AND ENABLEMENTS

The group discussed barriers/challenges and enablements for achieving the project intentions based on the following questions posed by the facilitator: 1) What would hinder achieving the project intentions? 2) What would help achieve the project intentions?

5.1 Barriers/Challenges

The participants were asked, “What would hinder achieving the project intentions?” Some of the general concerns included the ability to maintain consistent business rules; reluctance to change; quality of the data; usability of the EHR; and, that science is moving faster than the cancer community and we may not be needed in 5 years.

Barriers that impact the hospital registry:

- Enforcement of national standards and the implementation issues at the hospital and non-hospital reporting sources.
- Impact on hospital registry personnel – personnel changes, education, training, and computer skills.
- Hard to prioritize this project with all the other standards that a hospital has to integrate.

Hardware/software/IT barriers

- There are competing health information systems with development differences.
- Getting multiple software systems and/or networks to be able to communicate in a common language.
- Identifying variability of CCR in terms of their IT structure and find common denominator.
- Hardware availability.
- Currently, there are no standards for HL7 transmission and interpretations of the HL7 standards are different by institutions.

Cost barriers:

- Many small players with their own proprietary software have financial barriers to become standardized.
- Different standards and business rules for automated processes increase IT costs and sometimes these costs are hidden.

- There will be an implementation cost. How do you implement the EHR concept to make everybody (Hospital, pathology laboratory, other reporting sources) report the same/produce the same type of output?
- The total ownership cost.

Other barriers:

- Operations resulting from MERP will change required skills. People must have greater technical and analytical skills, which will impact recruitment.
- Definition, scope and objective are extremely general and broad; therefore, there is not sufficient time to complete this project.
- There is no overall authoritative body - lack of a strong center or coordinating group that has the ability to reach executive decisions.
- Data ownership. Who takes the responsibility if there is a change or addendum and who ensures that any change in data are transmitted?
- There is no national agreement on unit of analysis of patient record or event record to be sent to registrars.
- There are multiple standard setters. What do we do if we pick the wrong standards?
- Impact on volunteer time to set standards and educate staff. How do we find time, make time, and fund time to do all of this?

5.2 Enablements

The participants were asked, “What would help achieve the project intentions?”

The fact that the cancer community has a strong track record for developing standards, collaborating, and utilizing shared resources will make it easier to educate stakeholders of this project and enable standardization across the board. There is a political will to move national health initiatives forward as well as a strong interest in support of this project to help achieve the project goals.

Technological enablements presented:

- As technology becomes more and more standard, we won't have to invent things from scratch.
- Explore possible infrastructure resources that are within the department e.g., CCR may not have SQL server, but could borrow space from a server or system.
- Adopt open source standards to help achieve project intentions (do not have proprietary license restricting use of standards) e.g., type of machine readable record that has proprietary format that cannot be used by other systems.
- Limit software solutions for each process to reduce complexity.
- Utilize long-term partnerships with software vendors.

Enablements for data use:

- Easy accessibility and availability of data that can be linked from different data sources e.g., hospital discharge data.
- Look at upcoming ways to collect/analyze data e.g., web services and URLs.
- The amount of cancer data available from clinical research is expanding. If we can provide a national resource that catalogs data this will be more useful to public health and science.

Other enablements:

- Change regulations at the state, federal and international levels to change standards or mandate reporting.

- EHR and the diverse capability of handling multiple diseases are key in making this project happen.
- Availability of funds to do this project would help achieve project intentions.
- Opportunity/need for education from the lowest level up.
- Finite set of fields that are not fuzzy/separate distinct fields will make design easier.
- Clear means for collecting, collating and disseminating the information on advancement of products, to drive our efforts now and going forward.
- Ability to clearly define data collection rules.
- Develop standard business rules for all production processes.

6 CORE CCR FUNCTIONS

A list of core CCR functions developed prior to the meeting was presented to the participants. The participants reviewed and discussed the list and made modifications. The following is a list of the core CCR functions identified by participants:

- Receiving Event Reports
- Case Finding (passive and active)
- Consolidation
- Follow Back
- Patient Linkage
- Abstracting and Coding
- Audits/QC/QA
- Rapid Case Ascertainment
- Source Record and Cancer Level Editing
- Tumor Linkage
- Death Clearance
- Data Enhancement
- Calls for Data
- Data Use
- Follow-up
- Research Linkage
- Training
- Security, Privacy and Authentication Policy Requirements

Action item: determine which term to use Case Finding vs. Case Ascertainment. There was discussion on whether Case Finding should be changed to Case Ascertainment. It was suggested that Case Finding is more of a hospital registry term.

The participants agreed that Decision Making is part of each core function process and not a separate function. Decision Making will not be included in the list of core functions.

There is not a separate core function for Management Reports. It was agreed that Management Reports is part of the Audits/QC/QA core function.

The participants were asked to prioritize these core CCR functions to determine which core function would be modeled first (see Appendix B). Each participant selected their top 3 functions. The following 3 core functions received the most votes: Receiving Event Reports, Case Finding, and Consolidation. A second vote on the top 3 core functions determined that Receiving Event Reports would be the first function to be modeled.

7 RECEIVING EVENT REPORTS

The group discussed their As-Is processes for Receiving Event Reports. Then, the group discussed the To-Be process for Receiving Event Reports electronically and developed the process table (section 7.1), decision tables (section 7.2) and the business rules (section 7.3).

7.1 Receiving Event Reports Process

| ID | Name | Trigger | Description/Policies/Business Rules | Processor |
|------|---|--|---|---------------------------------------|
| 1.0 | Define Standards for Data Sources | | <ol style="list-style-type: none"> 1. Look at existing standards for potential use 2. It would be beneficial to have a national unique identifier to link patients 3. Not a trivial task to come up w/standards even amongst ourselves 4. Communicate w/EHR initiatives – need to participate on HITSP | |
| 2.0 | Enter Event Report | | <ol style="list-style-type: none"> 1. Some data sources enter event reports into a web-based application. 2. Data sources w/out registry-type operations | Data Source via web |
| 3.0 | Generate Event Report | | <ol style="list-style-type: none"> 1. Other Data sources generate reports using HL7 CDA templates according to defined standards for data sources. | Data Source via electronic submission |
| 4.0 | Log Event Report | Event Report received electronically | <ol style="list-style-type: none"> 1. All event reports received are logged in and the status marked as received. | |
| 5.0 | Determine Record Format | Event Report logged | <ol style="list-style-type: none"> 1. Determine what format the file/record is in. 2. Candidate formats include: <ul style="list-style-type: none"> – NAACCR current version – NAACCR prior version – EHR known format – Other known format – Unknown format <p>See 1.0 Decision Table</p> | Automated |
| 6.0 | Convert Data Values | Data Record in EHR or other known format | <ol style="list-style-type: none"> 1. Convert the data values to NAACCR values for records which are received in a known format that is not the current NAACCR format. | Automated |
| 7.0 | Determine If Record Accepted | Data Record in acceptable format | <ol style="list-style-type: none"> 1. Determine if a record can be accepted. <p>See 2.0 Decision Table</p> | Automated |
| 8.0 | Reject Event Report | Data Record in previous NAACCR format or Unknown format | <ol style="list-style-type: none"> 1. Reject the record and notify the data source. | Automated |
| 9.0 | Provide Source Record to State of Residence | Patient is resident of a state with data exchange agreement | <ol style="list-style-type: none"> 1. Patient's state of residence is based on his primary address. 2. If the patient is resident of another state with which there is a data exchange agreement, send the source record to that state. | |
| 10.0 | Record Error | Data received is duplicate record, or minimum data not supplied. | <ol style="list-style-type: none"> 1. If a record is a complete duplicate or if minimum defined data was not included, store the record with the non-accepted records, record the reason and notify the Data source. | |

| ID | Name | Trigger | Description/Policies/Business Rules | Processor |
|------|--------------------------------|---------|---|-----------|
| 11.0 | Capture event | | 1. Processes 11.0 & 12.0 were a proposal from one SME. Due to the lack of time, the proposal was not presented to the group for discussion. | |
| 12.0 | Extract analytical information | | | |

7.2 Receiving Event Reports Decision Tables

Decision Tables: review the decision tables (1.0 and 2.0) by going down the column, in the Condition section each condition with a Y means ‘Yes, this condition is true’ and N means ‘No, this condition is not true’, in the Actions section each action with a √ means ‘for the condition(s) represented as the Y/N in the column above, this action is performed’.

| 1.0 Decision Table: Determine Record Format, Convert Data Values, and Reject Report | | | | |
|--|---|---|---|---|
| CONDITION | A | B | C | D |
| In current NAACCR format: Y/N | Y | N | N | N |
| In previous NAACCR format: Y/N | - | Y | N | N |
| In other known format: Y/N (E.g. EHR, AIMS/Epath, Pathology, Death tapes, hospital correction record) | - | - | Y | N |
| ACTIONS | | | | |
| 1. Go to Validate | √ | | | |
| 2. Reject report | | √ | | √ |
| 3. Convert data values to NAACCR values | | | √ | |
| 4. Store orig. data values | | | √ | |

| 2.0 Decision Table: Determine if Record Accepted | | | | | | | |
|--|---|---|---|---|---|---|---|
| CONDITION | A | B | C | D | E | F | G |
| Duplicate Record: Y/N | Y | N | N | N | N | N | N |
| Reportable Condition: Y/N | - | N | N | Y | Y | Y | Y |
| Cancer terminology in record: Y/N | - | Y | N | - | - | - | - |
| Minimum Data Supplied: Y/N | - | - | - | N | Y | Y | Y |
| Patient Info Included: Y/N | - | - | - | - | N | Y | Y |
| Resident of Registry’s Population area: Y/N | - | - | - | - | - | Y | N |
| ACTIONS | | | | | | | |
| 1. Mark as non-reportable | | √ | | | | | |
| 2. Delete record (HIPAA compliance) | | | √ | | | | |
| 3. Request Patient Info | | | | | √ | | |
| 4. Log as received & Mark as duplicate | √ | | | | | | |
| 5. Notify source of error & reason | √ | | | √ | | | |
| 6 Accept Source Record & notify Data Source | | | | | | √ | √ |
| 7. Send to State(s) w/ exchange agreements | | | | | | | √ |

7.3 Receiving Event Reports Business Rules

| |
|--|
| Use Case ID: |
| Use Case Name: Receive Event Reports Electronically |
| Goal: To accept event report records with reportable cancer conditions. |
| Pre-Conditions: 1. Report is from a trusted source |
| End Conditions: 1. Event report record has been accepted to go forward. |
| Actors: 1. CCR software 2. Data Source software |
| Triggers: 1. Event report has arrived electronically from a Data Source. |
| Priority: |
| Frequency of Use: |
| Background: |
| Includes: |
| Exceptions: • |
| Special requirements: • |
| Assumptions: • |

| # | Main Scenario | Alternate Scenarios | Business Rules/ Remarks |
|----|--|---|-------------------------|
| 1. | CCR receives an event report from a Data Source electronically. | 1a.1 CCR pulls an event report from a Data Source. | |
| 2. | CCR logs record as received. | | |
| 3. | CCR determines the event report is in the current NAACCR format. | 3a.1 Not a known format or previous NAACCR format 3a.1.1 Reject the report 3a.1.2 Notify Data Source of rejection 3a.1.3 End of use case 3a.2 Electronic Health record or other known format 3a.2.1 Store original data values | |

| # | Main Scenario | Alternate Scenarios | Business Rules/Remarks |
|----|--|--|------------------------|
| | | 3a.2.2 Convert data values to NAACCR data values (if necessary) | |
| 4. | CCR determines that minimum data has been supplied. | 4a.1 Minimum data not supplied 4a.1.1 Record error 4a.1.2 Notify Data Source of error and reason 4a.1.3 End of use case | BR02, BR05 |
| 5. | CCR determines that the record is not a duplicate. | 5a.1 Duplicate record 5a.1.1 Mark as duplicate 5a.1.2 Notify Data Source of error and reason 5a.1.3 End of use case | BR03 |
| 6. | CCR determines that the record is for a reportable condition. | 6a.1 Not a reportable condition 6a.1.1 CCR determines that record is a relevant cancer data report. 6a.1.1.1 Mark relevant cancer data report as non-reportable. 6a.1.2 CCR determines that the record is a non-cancer related data report 6a.1.2.1 Delete Non-cancer related data report record 6a.1.3 End of use case | BR01 |
| 7. | CCR determines that patient is a resident of the registry's population area. | 7a.1 Not a resident 7a.1.1 CCR determines that data exchange agreement exists with the patient's state of residence. 7a.1.2 Send record to state of residence. | BR04 |
| 7. | CCR accepts source record. | | |
| 8. | CCR notifies Data Source of accepted record. | | |

| | Business Rule Statement | Remarks/Links |
|------|--|--|
| BR01 | To determine if reportable follow requirements from the appropriate reporting manual provided by the state | |
| BR02 | Minimum data requirements vary by cancer registry, data source and type of event | Action: Need to define specifics in subsequent workgroups |
| BR03 | To determine duplicate, every field must match (i.e. field by field deterministic) | |
| BR04 | State residency is based upon principal residency at diagnosis | |
| BR05 | When minimum data is not supplied, some registries will hold the data and correct it later. | |

7.4 Receiving Event Reports UML Diagram

The Receiving Event Reports UML diagram will be placed here upon completion.

8 OPPORTUNITIES FOR IMPROVEMENT

Opportunities for improvement were captured throughout the session. Some were captured on the side as the high-level as-is process was being modeled others were documented during the 'opportunity for improvement' brainstorming session.

There were several opportunities for improvement discussed for physician reporting. The main concept was to reduce the quantity of paper coming in manually by providing a web based entry or gateway for physicians to report cases. Another physician reporting issue is physicians (or their staff) do not want to take the time to input data into systems or their practice is so small/rural they do not have web based capabilities in their office. Recommendations to address this issue:

- Train/certify high school students on confidentiality and data entry. Most high schools have computers with Internet access and trained students could complete the data entry/data submission tasks.
- Computerized Physician Order Entry (CPOE) is becoming popular. Support for pay for performance initiative is growing. We can support/push these initiatives to encourage physicians to become more supportive of providing good electronic data.
- Provide a nationwide standard bubble form (e.g., SAT test) which can be scanned in electronically. It would become part of the medical record to ease the entry of information for physicians, making this more accessible to reporting sources without Internet access.

Manual case submission processes could be improved. Some CCRs hold paper records for a time period before entering them and other CCRs enter all paper records with reportable conditions and let the computer match them. Automation of abstracting/coding for the reporting source would reduce the time necessary to enter information.

There is a need to standardize received/processed data. As healthcare sources move towards the EHR there will be more opportunities to build partial records from multiple sources that will eventually be combined into full records. Therefore, reporting sources would not be required to transmit an entire record format and standardized formats would be tailored for reporting sources. Currently some systems require conversion of records to a different format while other systems support different types of records. As standards are developed, we should consider adopting existing ones or providing tools to convert between standards (e.g., using billing data standards and extending UB91). One recommendation was to focus on open standards and move away from proprietary standards.

Government initiatives will recommend the use of EHR and all government agencies will have to use the Health Information Technology Standards Panel (HITSP) recommendations. The cancer community needs to identify the most effective entry point and actively participate in EHR initiatives to ensure the EHR standards address our needs.

The Health Level 7 (HL7) Clinical Document Architecture (CDA) was recommended by HITSP as a standardized EHR messaging transmission format. Currently the NAACCR Cancer Abstract Transmission work group is working on a pilot project to test the use of CDA to transmit data from the hospital registry to the CCR and to develop an implementation guide. Members of MERP participate on this work group.

Other opportunities for improvement include:

- There is not a standard transmission record for getting death records from vital statistics. This leads to a cumbersome process to match the death records.

- Storage is cheap. All submitted source records should be stored and available to use in the future. These source records could be used when checking duplicates.
- CCRs could receive data from central services, mini-locators or regional health information organizations (RHIOs).
- Real-time reporting - sources can push information to CCRs without creating an abstract; pre-populate fields in the abstract to ease entry (these could be used for things such as including people on clinical trials); automate editing processes; and, query reporting sources for updates.
- Software must be rewritten to make it easy to get useable input data.
- Pull full NAACCR 11 format from EHR. Start with partials and move towards full in 6 months down the road.
- Have different record for different types of cancer.
- Versioning – some states will auto-convert a format up to the current version and some states reject older versions.
- Minimal source validation for those sources we trust.
- The Certification Commission for Healthcare Information Technology (CCHIT) is providing certification criteria for ambulatory EHR systems.
- Capture and store ‘events’ that are produced as patient receive treatment and produce analytical records on the fly to satisfy our clients.
- Perform visual editing of 10% of all records which pass editing
- Develop a method to determine where path-only cases have received treatment.
- Develop a method to back out of matching when a wrong decision has been made.

9 SIDE ITEMS

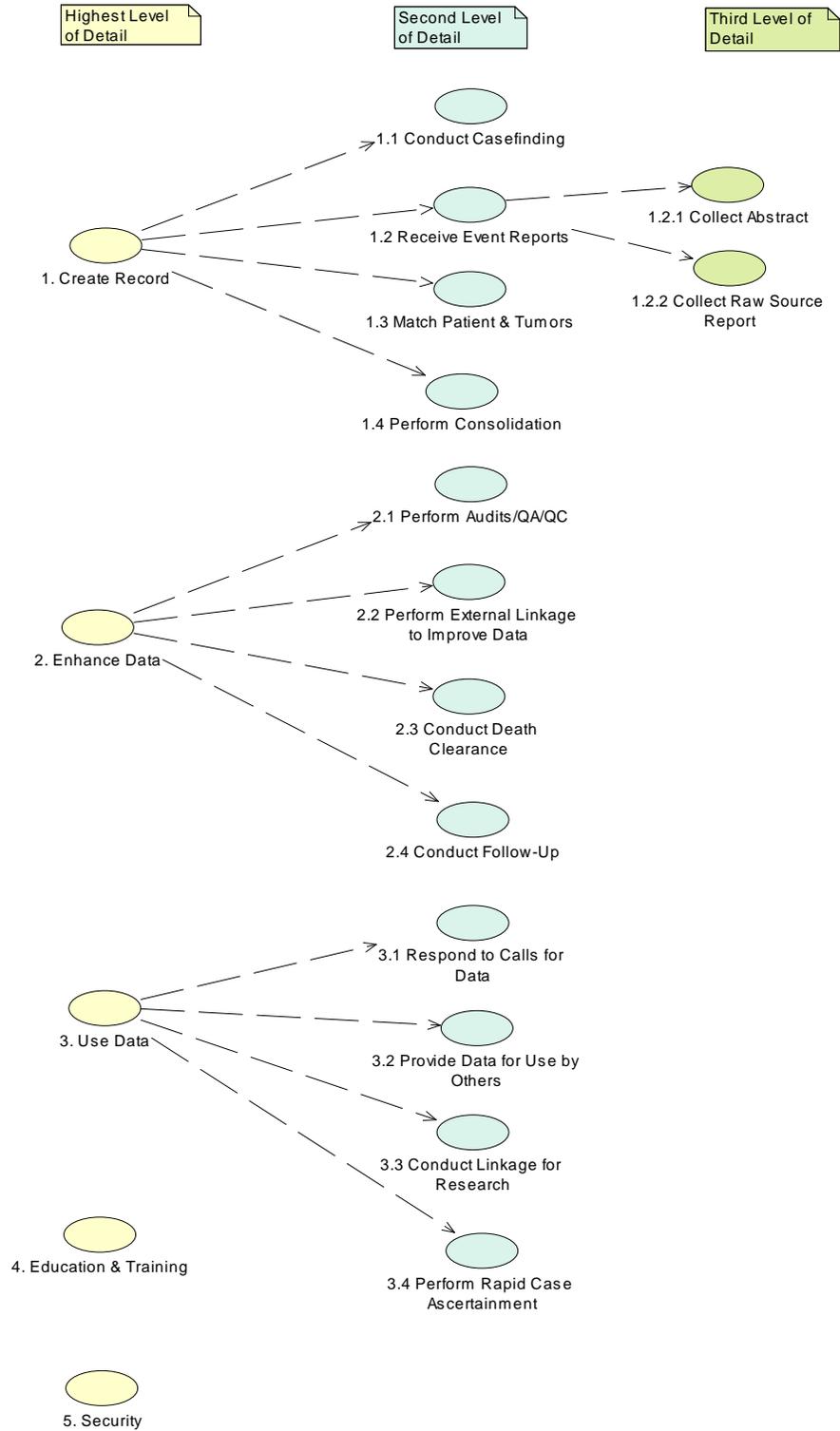
During the course of the SAMS the team identified items that could not be addressed during this event. These were noted on a side sheet for action later:

- Need to identify places where business rules don’t exist.
- NCRA workload workgroup will be doing surveys of all CCRs. They will ask questions like “how much time is spent doing Case Finding?” If we do not have common understanding of terms, then data will not be accurate.
- Make a list of standard-setting groups and determine how to participate.
- NPCR has a standard that requires CCRs to keep all submitted cases. This goes into effect on 2007.
- There is a parallel set of efforts to report on radiology reports, cost records, genetics, and infusion records. Opportunity to integrate. (Borders on the scope of integration). States (Medicaid/Medicare) are trying to link their claims to the cancer registry to see the average cost of treatment. Sometimes the first trigger is receiving a record from an Infusion center or Radiation center before we find out about a new cancer case.
- During subsequent meetings of MERP, would like to define specific minimum data requirements for each data source. This was flagged during Use Case discussions.
- There is disagreement between CCRs regarding the boundary of case finding.

10 APPENDIX A: CCR AS-IS vs. TO-BE OPERATIONS USE CASE DIAGRAM

Central Cancer Registry As-Is vs. To-Be Operations Use Case Diagram

Revised: 12-07-06



11 APPENDIX B: PRIORITIZED CORE CCR FUNCTIONS

The group prioritized the core CCR functions by making two voting passes. For the first pass, the group was asked to choose their top three priorities. Then a second voting pass was made to prioritize the top three functions. This priority was then used to determine which function should be modeled first.

| Core CCR Functions | Priority (pass 1) | Priority (pass 2) |
|--|-------------------|-------------------|
| Receiving Event Reports | 14 | 15 |
| Case Finding | 15 | 6 |
| Consolidation | 10 | 5 |
| Follow Back | 8 | |
| Patient Linkage | 6 | |
| Abstracting & Coding | 4 | |
| Audits/QC/QA | 3 | |
| Rapid Case Ascertainment | 2 | |
| Source Record & Cancer Level Editing | 2 | |
| Tumor Linkage | 2 | |
| Death Clearance | 2 | |
| Data Enhancement | 2 | |
| Calls for Data | 1 | |
| Data Use | 1 | |
| Follow Up | 0 | |
| Research Linkage | 0 | |
| Training | 0 | |
| Security, Privacy & Authentication Policy Requirements | 0 | |