

Requirements Findings

NPCR-MERP Central Cancer Registry Strategic Assessment and
Modeling Session (SAMS)

Atlanta, GA March 9 - 10 2006

CDC/DCPC/NPCR

National Program of Cancer Registries – Modeling Electronic
Reporting Project (NPCR-MERP)

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Prepared by: Technical Development Team

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BACKGROUND ON NPCR-MERP

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 to enhance efficiency, completeness, timeliness, and quality of cancer 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 (National Program of Cancer Registries (NPCR), Surveillance, Epidemiology, and End results (SEER), Commission on Cancer (CoC), North American Association of Central cancer registries (NAACCR)).

Phase I of the project began as a collaboration with the Virginia Commonwealth University Hospital System (VCUHS), the Virginia Cancer Registry (VCR), the National Cancer Institute 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 project outcomes are to:

- Develop a national plan or blueprint that will identify priorities to make better use of cancer surveillance resources and provide guidance for development of standards-based systems for cancer registration;
- Improve the completeness, timeliness, and quality of cancer data;
- Reduce costs significantly over time;
- Reduce the number of manual processes and make better use of Certified Tumor Registrars' (CTRs) time; and
- Improve data exchange between systems through the use of industry standards

PARTICIPANTS

Rana Bayakly
Program Director
Georgia Cancer Registry
arbayakly@dhr.state.ga.us

Lori Havener
Program Manager of Standards
NAACCR, Inc.
LHavener@naaccr.org

Jeannette Jackson-Thompson
Operations Director
Missouri Cancer Registry
jacksonthompsonj@health.missouri.edu

Amy Kahn
Epidemiologist
New York State Cancer Registry
ark02@health.state.ny.us

Marlys Knell
Coordinator
North Dakota Cancer Registry
mknell@state.nd.us

Gary Levin
Director of Administration
Florida Cancer Data System
Glevin@med.miami.edu

Jill MacKinnon
Director
Florida Cancer Registry
jill_mackinnon@miami.edu

Paula Marshall
Oklahoma Cancer Registry
PaulaM@health.ok.gov

Jim Martin, PhD
Director
Virginia Cancer Registry
jim.martin@vdh.virginia.gov

Linda Mulvihill
Program Consultant
National Program of Cancer Registries, CDC
Epe9@cdc.gov

Stacy Nelloms
Director
Maryland Cancer Registry
nelomss@dhmh.state.md.us

Lilia O'Connor
Operations Director
California Cancer Registry
loconnor@ccr.ca.gov

Bruce Riddle
Program Director
New Hampshire Cancer Registry
Bruce.L.Riddle@Dartmouth.EDU

David Rousseau
Maine Cancer Registry
davidr@hari.org

Wendy Scharber, RHIT, CTR
Consultant
Registry Widgets
wks_ctr@yahoo.com

Molly Schwenn, MD
Medical Director
Maine Cancer Registry
molly.schwenn@maine.gov

Donald Shipley
Manager
Oregon Cancer Registry
donald.k.shipley@state.or.us

Bette Smith, BTM, RHIT, CTR
Program Chief
Cancer Registry Ohio Department of Health
bette.smith@odh.ohio.gov

Roger Tenney
Program Manager
Tennessee Cancer Registry
Roger.Tenney@state.tn.us

OBSERVERS

Mamie Bell
IT Specialist
National Center for Public Health
Informatics, CDC
mbell1@cdc.gov

Wayne Brathwaite
Public Health Advisor
National Center for Public Health
Informatics, CDC
wbrathwaite@cdc.gov

Fran Michaud
Team Lead, ORTAT
Cancer Surveillance Branch, CDC
fmichaud@cdc.gov

Gayle Clutter
Program Consultant
Cancer Surveillance Branch, CDC
gclutter@cdc.gov

Missy Jamison
Epidemiologist
Cancer Surveillance Branch, CDC
mjamison@cdc.gov

Judy Qualters
Branch Chief
Environmental Health Tracking Branch, CDC
jqualters@cdc.gov

Joseph Rogers
Team Lead, Data Analysis Support Team
Cancer Surveillance Branch, CDC
Jrogers@cdc.gov

Patrick Wall
Computer Scientist
Environmental Health Tracking Branch, CDC
pwall@cdc.gov

Phyllis Wingo, Ph.D., MS
Branch Chief,
Cancer Surveillance Branch, CDC
Pwingo@cdc.gov

Facilitation Team

Minal Agrawal, MS
Business Analyst
CDC-Northrop Grumman
magrawal@cdc.gov

Timothy Carney, MPH, MBA
Informatics Specialist
Northrop Grumman IT
tcarney@cdc.gov

David Lyalin, Ph.D.
Consultant
Northrop Grumman - CITS
dlyalin@cdc.gov

Sandy Thames
Public Health Advisor
Cancer Surveillance Branch, CDC
sthames@cdc.gov

Facilitator

Alistair Cockburn
acockburn@aol.com

SAM SESSION GOALS AND OBJECTIVES OVERVIEW

- **Project Approach**

Strategic Assessment Sessions

For each identified core function of the central cancer registry, we carried out a series of facilitated discussions aimed at providing specific and detailed feedback on the following:

- Examples of acceptable or best practices in electronic reporting
- Examples of situations and circumstances to avoid or overcome in the move toward electronic reporting
- Technical, organizational, and content-based barriers to address
- A review of what might be possible in the next five years related to electronic reporting
- Issues, concerns, and recommended next steps

The sessions consisted of a combination of targeted discussion and free flowing brainstorming sessions among the entire group. At the end of each session, comments were reviewed for precision and a simple voting scheme was used to achieve group consensus on the priority and level of importance of the comments.

The sessions were recorded on paper notes that the NPCR-MERP Technical Development Team members collected and later consolidated into the Comments Section of this document. The Technical Development Team also used one scribe and two recorders to capture the comments made by the large group during the review and presentation of findings. These rough notes were posted throughout the room for continual display, review, and updating.

Model/Diagram Review Sessions

The Technical Development Team members presented several diagrams for review and comments. These sessions were conducted with the entire group and began with a Technical Development Team member providing a brief overview of the diagrams. All members of the panel were provided with paper copies both before and during the session to ensure they were able to follow the review closely. After the overview, the larger group provided comments, and suggestions, and also expressed concerns or criticisms of each diagram presented. The diagrams were:

Master Context Diagram – Highest level view of NPCR-MERP and the reporting relationships. This diagram featured a macro level representation of the principle agents involved in the national cancer surveillance framework including the hospital, the central cancer registry, the national cancer programs, and the patient.

Virginia Cancer Registry As-Is & To-Be Diagrams – Provided a non-technical, simplified view of the process flow for central cancer registry reporting as it exists today (both manual & electronic) and as it will exist after the PHIN-compliant messaging standards are introduced.

Central Cancer Registry (CCR) Domain Diagram – Highest level view of the central cancer registry data flows. This diagram presented the highest level CCR-specific components that contribute to central cancer registry operations and their relationships.

Central Cancer Registry Use Case Diagram – A general overview of the core components of central cancer registry data flow. This diagram presented the highest level CCR-specific components that contribute to central cancer registry operations.

Automated Case Finding – A detailed look at the sub-process of case finding in an ideal environment.

Business Workflow Activity Diagram – A detailed examination of CCR operations as data moves throughout the system.

SESSION OUTLINE OF EVENTS

THURSDAY Afternoon

- Participant Introductions
- NPCR-MERP Project Overview
- Review Diagrams
 - Context
 - As Is / To Be
 - Use Case/Functions

FRIDAY

- Review Diagrams
 - Central Cancer Registry Domain
 - Automated Case Finding
 - Business Workflow
- What Slows Timeliness
 - Issues for IT operations
- Changes to Central Cancer Registry
 - Structure of the Organization
 - Personnel
 - Relations
 - Role of Registrar
- Early Opportunities
- Next Steps

SAM Session Procedures and Methods

Model/Diagram Methods Overview

The presentation of each diagram followed the same format.

- The diagram was presented in overview (intent or purpose, key notation, and scope).
- Comments and questions were addressed.
- Corrections and updates were to be made following the session, presented in this report, and again during the Hospital Use-Case Web-conference.

Please see the Appendix for the summary of comments and suggestions for each diagram presented and the updated versions of each diagram.

Strategic Assessment Methods Overview

The NPCR-MERP Technical Development Team and the facilitator spent a great deal of time identifying core CCR functions. These functions were listed and additional time was spent on reaching a collective understanding on exactly what each functional topic area encompassed.

Additionally, the facilitator slowly walked the group through the first few functional discussions to familiarize participants with the methods. This step-by-step method allowed the participants to sort through issues of ambiguity, and to begin to brainstorm on the information the Technical Development Team sought. Subsequent sessions were much shorter but produced equally significant output. This method allowed for a tremendous amount of detailed information to be recorded for further analysis and review by the Technical Development Team.

Session outputs were recorded using several methods:

- Typed text of large group comments recorded in real-time by the scribe
- Handwritten notes of the large group comments recorded in real-time on large post-it display sheets
- Handwritten notes from participants derived from their various small group and individual assignments in response to facilitator instructions

Synthesis of Central Cancer Registry Use Cases (Core Procedures/Functions)

Casefinding

Purpose: Identify reportable cases of cancer from hospital and non-hospital data sources

Participants indicated that 100% electronic submission from reporting sources is currently being performed so there is a high probability for central cancer registries (CCR) to successfully implement electronic reporting. Participants differentiated between large facilities and small facilities in their opinions about successful implementation. Smaller hospitals, physician offices, nursing homes, and smaller, private pathology laboratories are less likely to be able to implement electronic reporting.

Participants felt that if the billing data in a facility is electronic, the facility has a high probability for performing casefinding and reporting electronically. Having the clinical data in a searchable format was a concern. Thus, some electronic medical records (EMR) are scanned copies of medical records, and are therefore images which can not be queried for specific diagnoses.

Rapid Case Ascertainment

Purpose: Identify cases of cancer from hospital and non-hospital data sources then report them shortly after diagnosis (i.e. within one day, real-time, etc)

Participants added this as a Use Case. One issue discussed was clarifying the definition of “rapid” and “real-time” reporting. The healthcare industry is currently working on standards which, when completed, the NPCR-MERP CCR participants can review and adopt if appropriate.

Participants discussed methods for implementing electronic rapid reporting. Discussions touched on developing criteria for rapid case selection using the EMR and discharge codes to identify potential cases, e-path reporting, and the need to obtain the reports even if there is only partial information.

Abstracting

Purpose: Create a source record containing required data items, including demographic, medical, treatment, and follow-up information

Two main issues were identified for the Abstracting Use Case:

1. What is the definition of electronic abstracting?
2. Is abstracting a core function of the CCR, needing its own use case?

Participants discussed whether *Abstracting* should be considered the actual

process of creating a source record by the CCR itself, without regard to the source (in-house or at the reporting source), or whether it should be considered a function of the reporting source alone, thereby defining CCR abstracting as the method of *receiving* abstracts from a reporting source. Participants agreed to defer these two issues to NPCR-MERP tech team for resolution.

Source Record and Cancer Level Editing

Purpose: Validate data values for consistency and accuracy

All participants use EDITS for validating source record data and felt that state-specific edits can help improve the quality of the data prior to reporting to the CCR. Participants also noted that identifying data quality and accuracy *errors* can be and is electronic, however, review and resolution of errors requires manual intervention.

Externally imposed requirements for manual (visual) review of source records is a major barrier, preventing some CCR's from fully implementing electronic editing.

Patient linkage

Purpose: Identify and link source records that refer to the same patient

Participants noted that identifying new cases and linking existing cases are currently performed electronically. Review of cases that fall between the upper and lower thresholds for match/non-match (possible match) must be performed manually by CCR staff. The major issue for patient linkage is the number of cases returned as possible matches, which can be affected by:

- The method of linkage (deterministic versus probabilistic)
- The presence of key patient identifiers
 - Date of birth
 - Social security number

The lack of patient identifiers is especially problematic on pathology report source records and with other non-hospital reporting sources.

Tumor Linkage

Purpose: Identify and link source records for the same patient that refer to the same cancer or possible subsequent cancers

Similar to patient linkage, tumor linkage can electronically identify new cancers and link existing cancers, with possible match cases requiring manual review. The participants stated that the new multiple primary rules being developed will improve electronic tumor linkage and felt that a tumor linkage module could be developed and shared between CCR's. It was noted that the quality of the data has an impact on the accuracy of the linkage as well as on the number of cases requiring review. Routine data audits have a positive impact on tumor linkage.

Consolidation

Purpose: Produce a single “best” value for each patient and tumor data item by selecting the best data from linked source records for the same patient and cancer

The participants felt that between 50% – 100% electronic consolidation could be performed. However, manual review and resolution of major discrepancies would be required. The NAACCR Record Consolidation subcommittee is preparing a Resource Guide for consolidating data items within a CCR which participants feel will be a useful tool for automating more of their consolidation processes. One participant noted that a probabilistic consolidation method needs to be used and that a certain *error rate* will occur which needs to be accepted as an outcome of increased automation.

Follow-Up

Purpose: Maintain long-term surveillance of patients for research purposes

The main issue discussed was that CCR's may perform active or passive follow-up, each having different capabilities for implementing electronic or automated processes. It was noted incidence-only CCR's do not perform follow-up (CCR). Follow-up in many registries is electronic up to the point of detecting a conflict, at which point manual intervention and resolution is required.

Death Clearance

Purpose: 1) Identify cancer cases not reported to the CCR and follow-back to appropriate reporting source for additional information; 2) obtain vital status information for the patient

The participants identified Death Clearance as a Use Case for the CCR. Linkage (matching) issues are the same as described above for the Patient Linkage and Tumor Linkage Use Cases. The consensus amongst participants was that everyone performs death clearance (follow-back) differently, causing wide variation in the results. Confidence in the quality and accuracy of the death certificate information plays a large part in the extent to which automation can be implemented. Electronic processes are currently being performed, including automatic follow-back of the non-matched patients or cancers and availability of death certificates online for physician review.

Currently, there is no national standard for Death Clearance; however, the NAACCR Death Clearance Workgroup is working on best practices documentation.

Data Enhancement

Purpose: Obtain and/or validate data items by linking with non-CCR databases

Participants identified Data Enhancement as a new Use Case. Similar to other linkages, the process of determining a match or non-match is automated, with the resolution of grayzone cases being performed manually. What makes this particular function different, however, is the wide variation in the completeness and accuracy of the patient identifier information; this creates a higher false-negative match rate. Careful evaluation must be performed prior to performing the linkage to ensure that required data items are present and are in a standard format. CCR's frequently have to recode or convert the external data to NAACCR standards (i.e. changing gender codes from M or F to 1 or 2, respectively).

Another major issue for automating data enhancement is determining which data value is best if the data value from the external source conflicts with the existing data value in the CCR. An acceptable definition of what is best must be explicit.

Participants specifically discussed geocoding when describing problems with data enhancement. Rural Route addresses and use of NAACCR's Census Certainty Code were both discussed.

Research Linkage

Purpose: Provide a resource for researchers to obtain information on their study cases

There is significant manual effort prior to the actual linkage, including obtaining Institutional Review Board (IRB) approval, data security issues, etc. Additionally, significant manual investigative work is performed to find mutually agreeable data formats and data items. A unique patient identifier number would greatly help all CCR linkage activities.

Audits/Quality Control

Purpose: Ensure cancer registration is complete, timely and of high quality

Audits for casefinding center on identifying all reportable cases. A complete EMR will allow automated casefinding to be performed more efficiently and accurately. Participants felt that use of SNOMED codes in the EMR and in the pathology laboratory will greatly enhance e-casefinding. Searching blocks of text was discussed, with participants indicating that Artificial Intelligence in Medicine (AIM) has this capability built into their E-path system. It works well but still requires manual review and confirmation of the identified potential matches. Developing a standard method to read and analyze blocks of text, then converting the text into

the appropriate codes for casefinding.

Re-abstracting audits are not amenable to further automation. The tools for re-abstracting are electronic – selection of cases, electronic data entry modules, analysis of data – however, health record review and data entry remain manual tasks.

The participants discussed several areas where quality control audits can be made electronic and automated, including timeliness audits, automated (canned) reports for certain errors, and various logic and edit checks. Certain specific quality control checks were brought up; examples are foremost common names, sex, and site-specific cancers. Many quality control audits require specific programming; additionally, the results often need a manual component for review and resolution.

Calls for Data

Purpose: Submit cancer information to various organizations to meet federal and state regulations and to assist in research activities. (Previously labeled Reporting)

The major barrier to automating this function is that changes to the standard(s) require a manual revision to CCR databases, software, and reports.

Data Use

Purpose: Perform statistical analysis on collected data to provide interpreted information on cancer for a particular population. (Previously labeled Analysis)

Participants felt that SEER*Stat helps automate analysis and data use. Because of changes in what is required to be reported, the software that creates the data files for SEER*Stat need manual revisions. Software to allow data exchange between databases and analysis tools would be useful.

Most data use tasks require extensive staff input to evaluate the issue to be analyzed, to identify appropriate data to be included in the analysis, and to ensure analysis will not lead to identification of patients. Interpretation of the results always requires human intervention. IRB approval is often required prior to analysis. The actual process of computing the resulting statistics is, of course, electronic and automated.

Training

Purpose: Educate personnel on cancer registry operations.

The participants identified training as a new Use Case.

Participants felt that training will require an increasing amount of time. The logistics of training – scheduling, providing materials, and constructing the training session – are manual tasks that cannot be automated easily.

Participants discussed the SEER and NAACCR web modules; one registry

provides internet training with PowerPoint presentations that have associated voice-overs; this method resulted in a 24/7 training opportunity. Automated feedback of errors to hospital registrars, and using error tracking data as training topics were suggested.

Consideration is needed regarding who may need training; different types of reporting sources required different types of training. In addition to training on national standards, there is always a need for state-specific training.

Of particular note was the concept of having a centralized training and education resource library. Participants discussed the development of a database of resources that are available and can serve as a clearinghouse for both new registrars and for directed training for existing staff.

Discussion on Opportunities for Change and Innovation

Issues for IT Operations

Participants were asked to discuss issues relating to IT operations that are adversely affecting timeliness. Major themes were identified.

Financial resources needed to implement or enhance electronic and automated functions in the CCR were a recurring issue through all of the IT barriers listed below.

Data Sources

Participants identified a variety of issues relating to data sources and electronic reporting:

- Many data sources are not available electronically
- The electronic medical record is not widely available
- External data suppliers may be unwilling to report
- There are no uniform data layout format or required data items for most data sources
- Data quality standards for data sources are lacking
- Much of the data is in text format which is difficult to process to identify cases accurately
- Implementation of electronic reporting is slowed by the facility's IT issues rather than by the CCR IT issues
- Funding to support electronic reporting will be necessary

Personnel

Lack of IT personnel was a major barrier to implementing enhancing electronic automation in the CCR. This included:

- Funding for IT personnel
- Lack of IT Staff – turnover, unfilled positions, not enough work for a full time position

- IT department and staff not under the control of the CCR
- Conflicting priorities of IT department
- Delays in upgrading software
- The CCR IT staff may not have the depth of knowledge and skills needed for e-reporting. CCR's must be able to compete to attract and retain the best IT staff

Changes in Standards

Frequent changes in reporting requirements and standards affect the CCR and the software vendors. The changes and subsequent errata to changes cause problems for modifying software and for releasing it in a timely manner. This in turn can influence when any newly accepted data standard is implemented, as well as the overall quality of data submitted. Often the changes snowball into many issues. For example, data conversions require varying amounts of manual review. Time, money, and personnel are needed to revise the software and convert data.

Software and Hardware Issues

- Financial resources for purchasing hardware and software and for upgrading software is limited. This, along with the bureaucratic processes involved in obtaining these resources in a timely manner, was identified as a key barrier for electronic reporting
- Software issues:
 - lack of a particular electronic/automated function within the software
 - timeliness of updated software
 - need for CCR IT support in validating and/or troubleshooting vendor software issues
- Hardware issues included the delays in receiving purchased hardware, physical space availability, and equipment reliability

Management/Legal Issues

There was concern whether the CCR has the legal authority to implement all of the activities discussed and whether management at the facilities would support reporting to the CCR. Understanding IT security needs at all levels, along with the amount of red tape needed to implement these activities, are important issues.

Specific IT Barriers

Many specific examples were identified as IT issues for NPCR-MERP. These are:

- The lack of variables for linkages with data sources
- Linkage resolution takes time and the differences across data sources will increase the amount of time required.
 - A national personal ID would make linkage more accurate

and more efficient

- The need for more complete data schemas, models, programs, and modules for tasks, including more shared code and program pools, consolidation rules for data items and for format version compatibility – HL7, etc.

Changes to Central Registry

Participants were asked to discuss changes to the CCR in an enhanced electronic/automated environment. There were four broad categories, including Organizational Structure, Personnel, Role of the Registrar, and Relationships.

Organizational Structure

Participants discussed organizational acceptance of change to a more electronic environment.

- Operational processes may need to be revised.
- The EMR will cause a major change to how CCR's perform their activities.
- Some existing organizational structures need to continue, such as cancer registries in a university setting where data needs to continue being reported directly to the CCR, rather than going through the state department of health or human services

Participants noted that there would be start-up costs for new electronic or automated system and increased costs for data exchange and security. Cost shifts in resource allocation within the CCR would be needed to accommodate more varied reporting source data and for changes in types of personnel. The CCR will need to take an active role in cancer education efforts. The CCR will be able to provide registries and studies or trials with electronic follow-up data. Physical structural changes to offices and facilities may be needed because workflow will be different. Better servers and security systems may be needed to accommodate increased data transfer. There may be a need for more inter-platform communication between computer systems and more flexibility in receiving and parsing data.

Participants also noted that there will be more accountability for work that is driven by objective data, rather than subjective observations and opinions. With a data-driven analysis of processes there could be increased legislative support for the cost of the CCR. With data collection occurring in a more timely manner, clinical trial and other data users will see the benefits of cancer information that is more rapidly available and additional financial support may be forthcoming.

Personnel

- **Data Users**
More epidemiologists and researchers will be needed to use data. There may be a need for public relations staff as the CCR's interact with a greater variety of data users and sources.
- **IT Personnel**
More IT people need to be dedicated exclusively to central registry functions. Participants felt this would be best accomplished by establishing IT units in the central registry and increasing the amount of IT support. CCR's can no longer make do with their own limited IT capacity. IT staff are going need to know more about cancer as a disease, and the standards used, with closer communication between IT and other registry staff so IT staff understand needs. All CCR staff will need to stay current with standards and the progress of healthcare IT initiatives.
- **Registrars**
Participants expressed concern about the about shortage of CTR's and the salary levels of CTR's. Electronic automation efforts will change the work and who can do the work, which will shift responsibility for many tasks. Re-organization of duties may be a major outcome. Different functions may be assigned to existing staff; some will embrace the change but others may not.

Participants viewed automation as an opportunity for education and job progression. Registrars can focus on what they are trained to do, working higher up the skill chain, rather than performing clerical functions. Their activities may be enhanced to include more analytical functions like report generation, trends analyses, and quality assurance/control. Currently the process may be isolated; for example, a task may be delegated to one individual. In the future, there may be more job sharing and joint responsibility for registry activities. There also may be more opportunities for telecommuting.

Changes to Registrar Activities:

- Data managers rather than abstractors
- Communicating to outside sources that this is a positive change; moving forward
- Expansion of role of registrar into clinical trials and research
- Change from dealing with data to dealing with people
- More time for tasks that currently are not adequately performed
 - Reliability issues from sources that do not have formal data quality programs

- Audits
 - Quality control
 - E-report generation
 - Data requests
 - Training facility registrars
 - Educating data users (i.e. the definitions and limitations of the data)
- Training
More training at all levels for all registry staff will be needed. The need for registrars to become technically skilled was the most frequently noted non-IT personnel issue. Other areas for training included cancer data use, current trends in cancer diagnosis and management (genetic testing, etc), writing technical procedures, and data use, analysis and limitation of data;

Participants discussed whether a change in educational levels may be needed, specifically whether training at the college level would be appropriate. This initiative may change the pathways for how CTR's come into the system. As CCR's move more to analysis and IT, there may be a shift in who is entering the registry profession. This could change office culture, create new dynamics, and influence salary. One possibility noted is a potential change away from a female-dominated profession.

- Implementation Issues
Registrar position descriptions need to be updated to include greater technological sophistication, data analysis skills, and the ability to perform education and training. Registrars, who are already underpaid, will be performing higher-level activities, requiring higher salaries. CCR's may be in competition with other healthcare partners (clinical trials and research projects) in hiring registrars with enhanced skills.
 - Once data is transmitted in real time, more staff will be needed at the CCR (for quality control, consolidation, etc.) and fewer staff at reporting facilities.
 - The role of registrar at reporting sources will turn to more reviewing and correcting instead of coding and abstracting.
 - The human resources logistics of dropping a position and recreating it as another type position can be problematic. Finding a way to replace people that leave, and retraining existing staff, are difficult issues. The possibility of outsourcing registry functions was noted. There will also be an increased cost for added IT staff.

Participants were concerned that implementing electronic automated functions may end people's careers if registrars or IT personnel are unable adapt to the new environment. Current staff have knowledge areas that are priceless, and it will be difficult to lose them. Additionally, management may be less likely to preserve CTR's in a more electronic environment. One participant noted that it would be "...best if we can find registrars who can program or a programmer who knows the registry and disease."

Relationships

- External Communication
 - Public relations within the registry and external to the registry will be needed to promote electronic automation as a positive change.
 - All partners need to be part of the system rather than feel they are being victimized by it.
 - Participants felt this initiative may improve and strengthen relations with large hospitals that are currently more IT advanced, but may strain relations with small and medium size hospitals whose IT resources which would need to be upgraded.
 - CCR staff will likely need to help hospital registrars communicate with facility IT staff. Better integration with hospital reporting systems will necessary

Data transfer will be faster; this will improve communications for all partners. Participants discussed whether relationships will become more formalized; a more formalized chain of custody for data transfer may develop. All partners will need to assume responsibility for activities. Security issues will require ongoing efforts.

CCR's will need to continue improving communication with external sources. Participants noted that it will be important to maintain communication with all reporting sources by phone and face-to-face; human communication is important when issues need to be resolved. CCR personnel will probably spend more time at non-traditional reporting sources. CCR IT staff will also need to develop a closer connection to IT departments in the state and the agency. CCR's will need to work very closely with standard setters (for standard vocabularies and codes, SNOMED, LOINC, NAACCR, CoC, NPCR, etc). Participants noted that it would be helpful for standard setters to expand the definition and rationale for the standards and make them easier to adopt to avoid wasting time and money and to avoid getting the data wrong.

Early Opportunities

Participants were asked to identify opportunities for implementing electronic and automated functions within the CCR in a short timeframe (1 – 3 years):

Electronic Pathology Reporting (Casefinding)

- Identify existing databases for casefinding that can be obtained electronically
 - Focus identification at hospitals where largest percent of data for CCR's is located
- Develop methods for electronic casefinding for other reporting sources
- Develop a data reporting format or record layout that data sources can use to report data to improve automated case finding
- Develop a data reporting format or record layout form using reimbursement data to supplement case finding/reporting requirements; need a national standard
- NAACCR should start developing HL7 standard for cancer abstracts
- Make electronic reporting software from Artificial Intelligence in Medicine (AIM) available at affordable cost

Other Registry Functions

- Develop documentation, models, and specifications for implementing electronic and automated processes
- Work with software developers to standardized registry operations
- Work with standard setters to
 - Reduce the need for annual changes
 - Disseminate documentation for changes in a timely manner to allow revision and implementation by the deadline
- Develop linkage standards, procedures, and cancer level edits (patient, tumor, consolidation)
- Automate death clearance and disease index linkage
- Work with pathology laboratories to encourage their coordination of billing with clinical data
- Improve interstate data sharing
- Develop a national agreement for National Death Index (NDI) access

Policy Activities

- Develop education and marketing tools for NPCR-MERP project – buy in
- Using data, impress upon policy makers the inefficiency of having multiple small vendors that do not speak with each other
- Gather a consortium of partners who are invested in this kind of process
 - Build a catalog of what has been done and is currently available
 - Prioritize efforts
 - Distribute activities to consortium members to develop functions for the benefit of all
- Find a funding source to build the IT infrastructure to implement NPCR-MERP
- Evaluate tying legislatively mandated e-reporting to reimbursement in order to get this implemented
- A data driven policy can help justify policy changes to make things more efficient.
- Evaluate enforcement practices amongst both small and large hospitals to mandate compliance
- Continue addressing security issues at all levels in the process.

Summary of Participant Reaction & Recommendations

Participants felt that they have a clearer, broader picture of the NPCR-MERP and appreciated having the scope and priorities defined. They felt that individual pieces of central registry activities are electronic or automated at varying levels; however, participants appreciated seeing how all the pieces are coming together in a unified effort. They were pleased that NPCR-MERP gotten to the point where the national dialogue begins.

Participants were happy to know that there is concurrent development of EMR and electronic central registry functions. There were concerns about whether the CCR's will have an effect on the development of EMRs and whether the EMR will have the data CCR's need.

E-path reporting was mentioned as an activity that will benefit from national standards and procedures being moved along by NPCR-MERP. Participants felt it was a great learning experience and enjoyed the opportunity to hear what is happening in other CCR's relative to electronic reporting. They identified items that can be implemented in their own registries to enhance automation.

Next steps in the NPCR-MERP CCR SAMS activity will largely center on convening the NPCR-MERP CCR SAMS Workgroup:

- Kickoff Web-conference is scheduled for May 9, 2006 at 2:30PM EST (call-in details to be provided)
- Begin planning for the next CCR SAMS event
- Work on developing the central registry portion of a formal Needs Assessment/Gap Analysis to determine the current state and identify priority areas for future NPCR-MERP activity.
- Systematically work with representatives from CCR's around the nation to complete the hospital domain modeling effort and to create a report of guidelines and recommendations to advance the initiative.

APPENDIX

Diagram/Modeling Session (Participant Comments, Suggestions, and Updates)

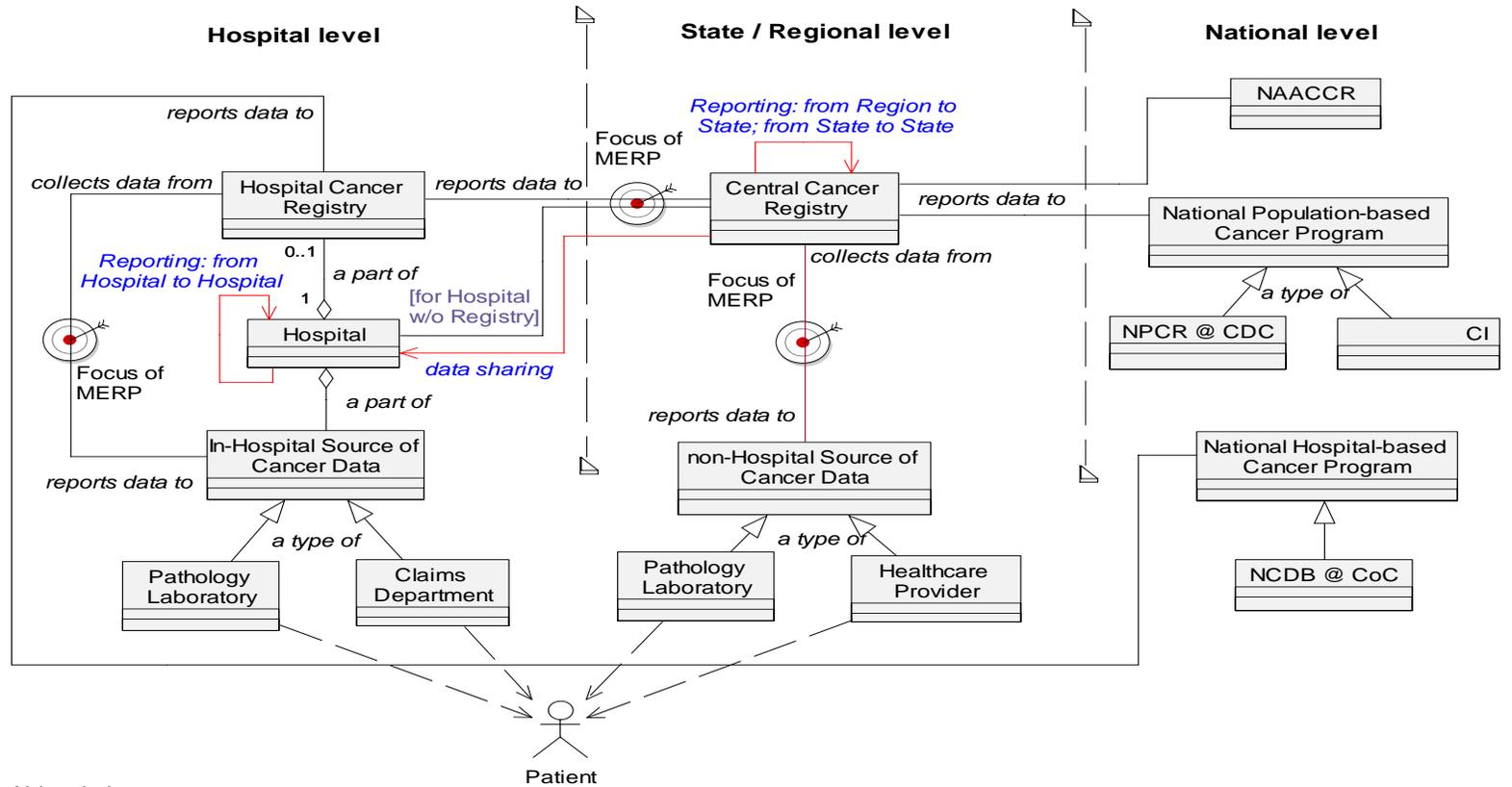
Pending task

Completed task

CONTEXT DIAGRAM				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
Add line that shows Central registry goes back hospital cancer registry	USE MORE COLORS wherever possible but make certain printing/copying restraints are taken into account.	What are bull's-eyes? ACTION: ADD bull's-eye to legend	This is the whole scope of the MERP? YES	Registry vendors allow data from hospital systems to be pre-loaded into the registry itself.
Send feedback to the central registry back from national level		Need to know what the Reporting Pathology Protocols (Phase 2) Project) (RPP2) is doing...May provide a cost-effective way of doing things	Why aren't there more non-hospital sources? <i>Response: This is a high level model. Hospital and path labs are the primary sources.</i>	Models will be linked together; Participants felt this would be a very nice feature
If reporting from hospital to hospital, there is also reporting from hospital to treating facilities		Ambulatory surgery center needed, along with other sources; Report to NAACCR is only required for certification (next to last paragraph)	A CoC approved program has to reflect cancer treatment in that catchment area. However, the registry no longer has access to the catchment area. The registries are going to make a link with non-hospital data sources so they can meet standards. Should this be added to the diagram?	

Cancer Registration: Context Diagram for the NPCR-MERP project

Revision Date: 02-07-06



Abbreviations:
 CDC: Centers for Disease Control and Prevention
 CoC: American College of Surgeons Commission on Cancer
 NAACCR: North American Association of Central Cancer Registries
 NCDB: National Cancer Data Base
 NC: National Cancer Institute
 NPCR: National Program of Cancer Registries
 SEER: Surveillance, Epidemiology, and End Results Program

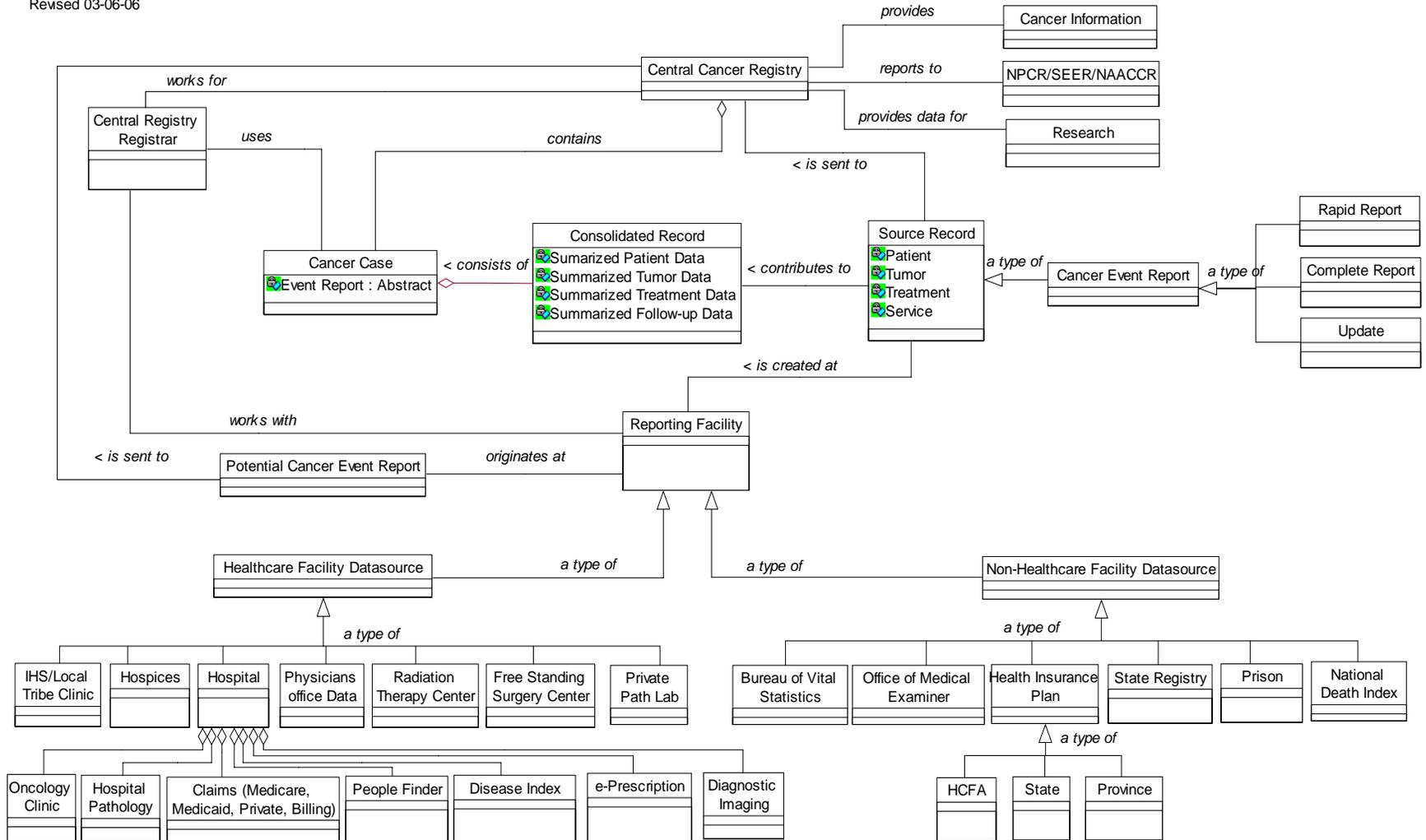
Pending task

Completed task

CENTRAL CANCER REGISTRY DOMAIN DIAGRAM				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
Add <ul style="list-style-type: none">Other Non-Hospital Sources: DMV, SSDI, Voter Registration, State Health Department		Add <ul style="list-style-type: none">An Insurance type: Insurance		
Add <ul style="list-style-type: none">Other Hospital Sources: RHIO, Freestanding Oncology Center, Nursing Home, Dept of Defense, Radiology, Radiation Therapy Center	Add	<ul style="list-style-type: none">Insurance type called "State". Change to Medical AssistanceHealth insurance plan: HMO		
Change <ul style="list-style-type: none">Private Path Lab to Freestanding Pathology Laboratory				
Add <ul style="list-style-type: none">To Entity : Consolidated Record Summarized Stage Data				

NPCR MERP Central Cancer Registry Domain Diagram

Revised 03-06-06



Pending task

Completed task

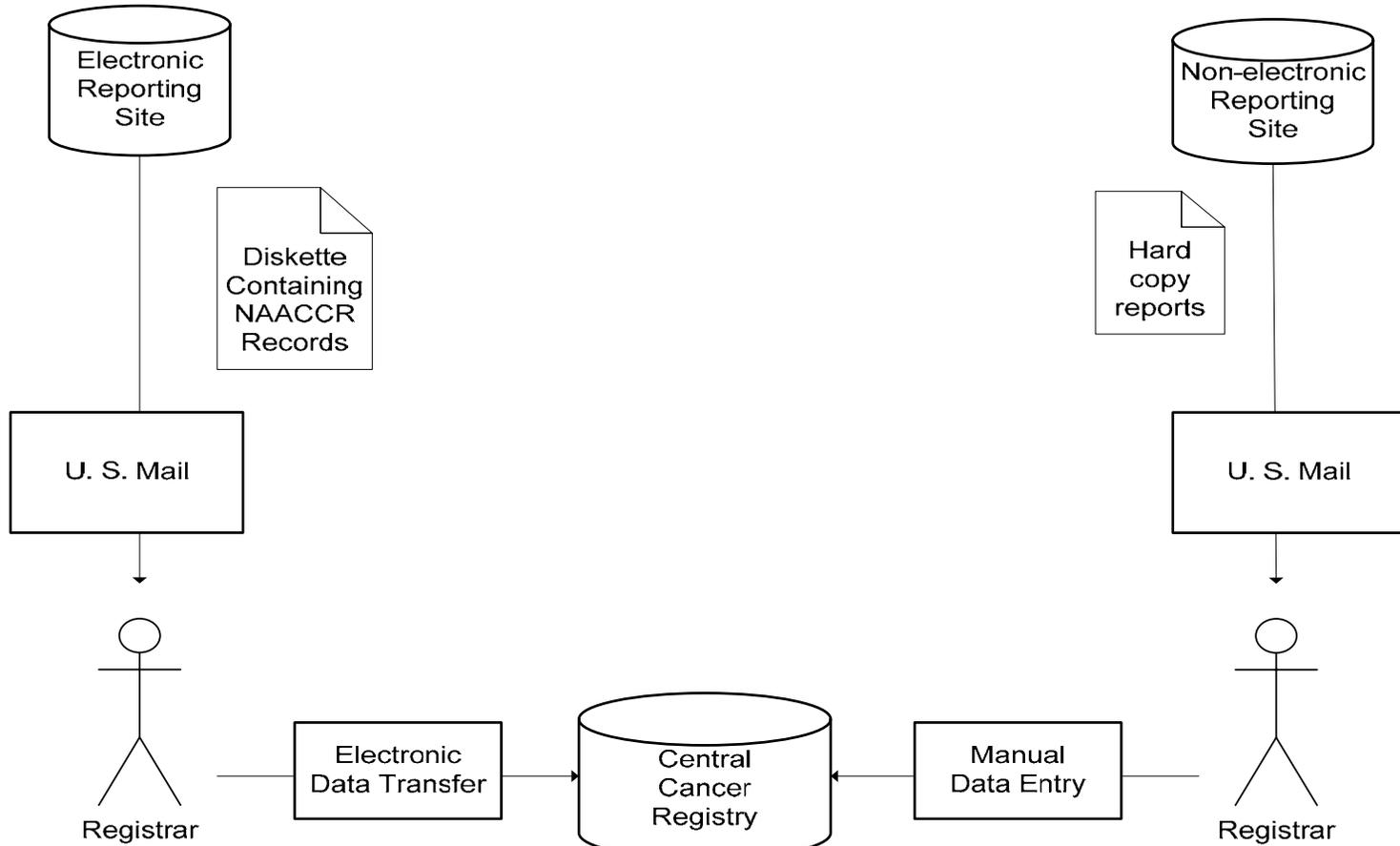
VIRGINIA CENTRAL CANCER REGISTRY (TO-BE & AS-IS) NON-UML DIAGRAMS				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
ADD on To BE Diagram: needs actor above REGISTRAR REVIEW AND PROCESSING		Why are there two registrars? (As-Is diagram) They are actually representing the same person.		Want to understand PHIN; <ul style="list-style-type: none">• A blueprint/cook book; how to build interoperable standard system.• CDC public health information network (PHIN) moving toward integrated standards based software; reduce duplication of effort.• PHIN-MS implements PHIN standards for message transport.
				NY using PHIN to get electronic messages. PHIN is a glorified ftp.

Pending task

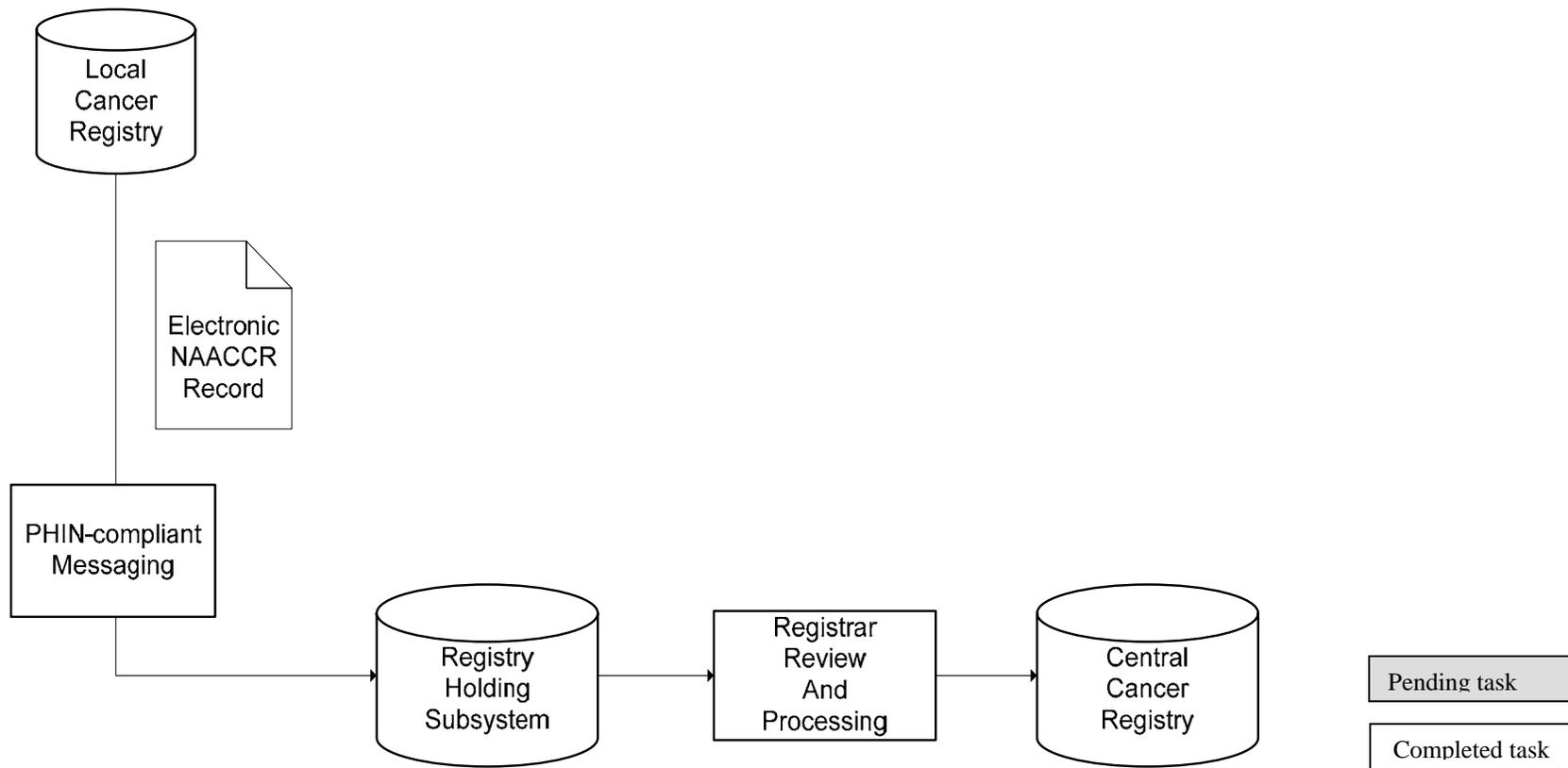
Completed task

VIRGINIA CENTRAL CANCER REGISTRY (TO-BE & AS-IS) NON-UML DIAGRAMS				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
				Transfers a file from one point to the other point.
				There was a general interest in PHIN details; table for now
				All this data coming in from PHIN; it goes to health department; what about university registry systems? It would be a step backward to go through state system to get data. Have IT throughout system to help work this through.
				Will CDC impose PHIN standards/system?

Non-UML VCU As-Is Diagram



Non-UML VCU To-Be Diagram



USE-CASE DIAGRAM

Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
<p>NEW Use Cases:</p> <ul style="list-style-type: none"> • Rapid Reporting • Data Enhancement • Training • Audit • Death clearance • Research linkages • Required record linkages • Data Use (data requests, etc) 		<p>Needed to re-direct participants on how to read the diagram; It is from a central registry perspective</p>	<p>Add Recipients:</p> <ul style="list-style-type: none"> • Researcher • Data Consumers • ACS • COC • Health Department 	<p>Data extraction for linkage to enhance data in the registry</p>
<p>Replace analyst with epidemiologist</p>		<p>Add arrow-heads on text to indicate how to read relationship</p>		<p>Two notes were written after the discussion on the Use Case Diagram:</p> <ol style="list-style-type: none"> 1. Regroup core CCR functions <ul style="list-style-type: none"> • Header – Consolidation, with patient linkage, tumor linkage and consolidation under it • Header – Audit, with casefinding under it 2. 13 participants may be confusing or conflicting levels of detail in the CCR Use Case Diagram:

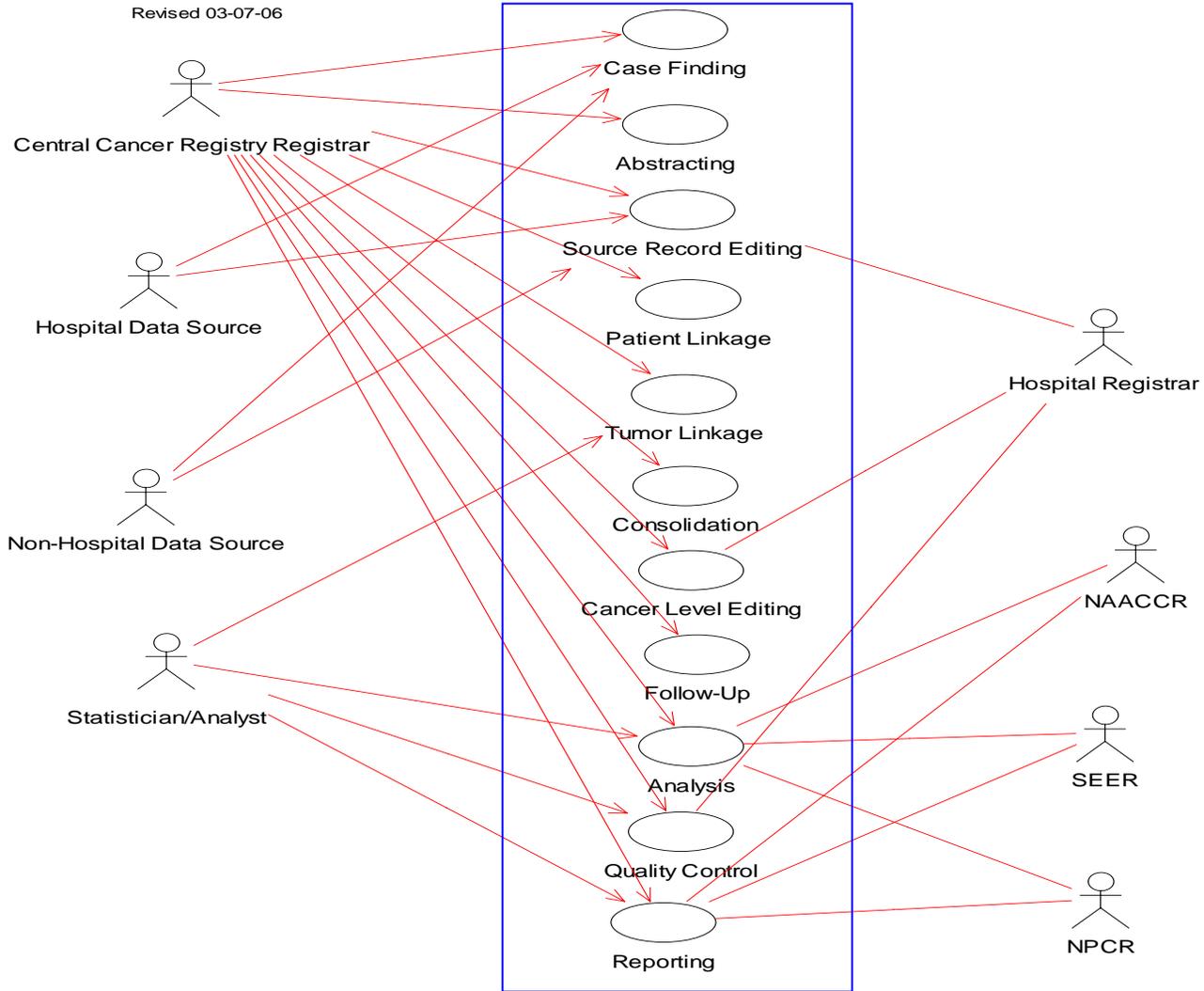
Pending task

Completed task

USE-CASE DIAGRAM				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
				Example: linkage is a function that can subsume patient, tumor and other cases.
Add <ul style="list-style-type: none">Data Manager as actor		Why line between statistician and patient linkage?		
Arrow going to casefinding to registrar; add line between statistician and patient linkage				

NPCR-MERP Central Cancer Registry Use Case Diagram

Revised 03-07-06

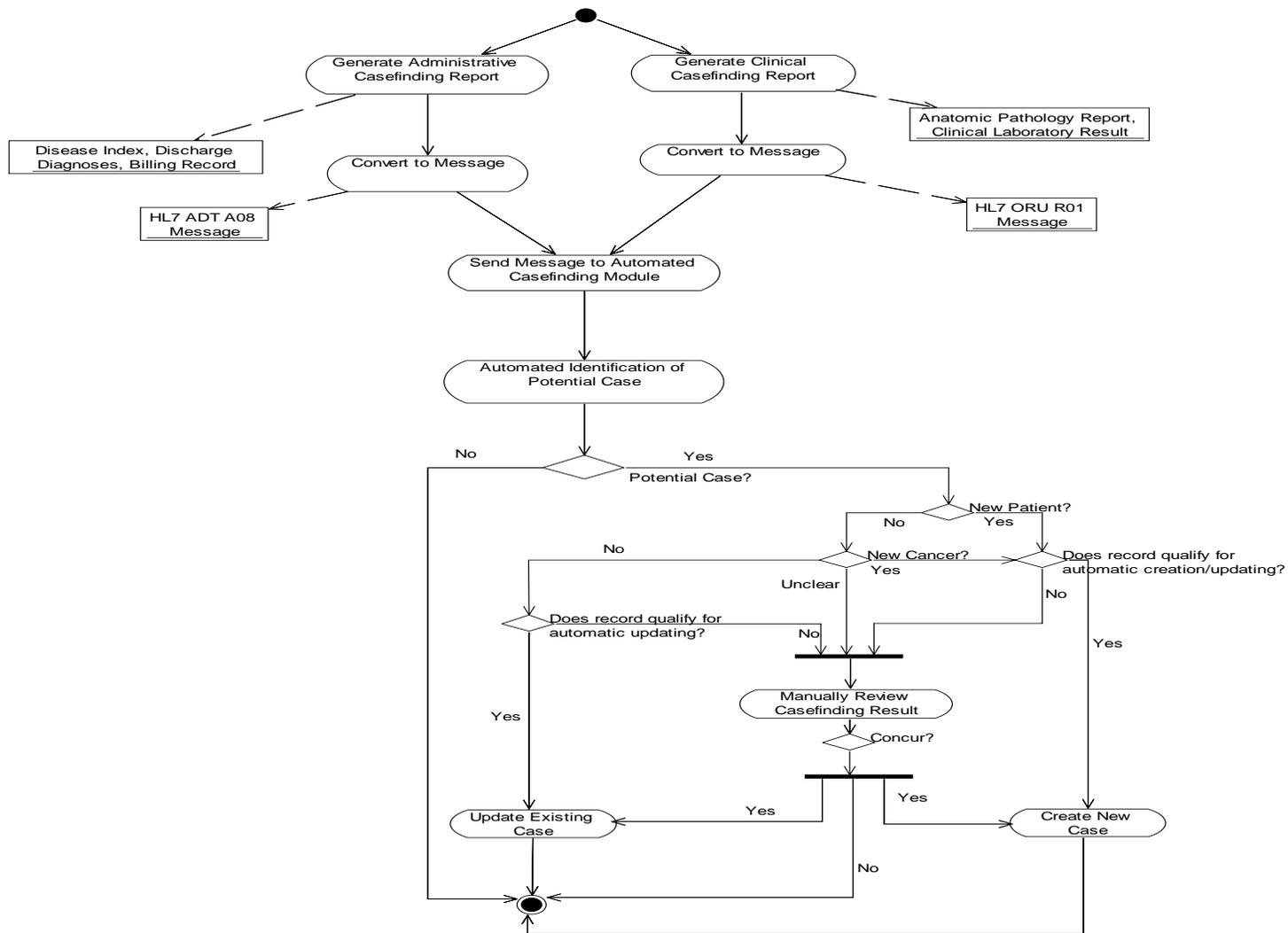


Pending task

Completed task

AUTOMATED CASE FINDING DIAGRAM				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
If two primaries are shown, can it be addressed?	Remove the arrow on all of the notes	How is suspense file addressed?		

Automated Case Finding Diagram
 Revised 01-25-06



Pending task

Completed task

BUSINESS WORKFLOW ACTIVITY DIAGRAM				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
Add: col 1 <ul style="list-style-type: none"> Need to add <i>Create New Tumor Record</i> process to Segment 3 	Move: col 4 <ul style="list-style-type: none"> Develop Rules and Standards to top of swimlane 	Add: col 2 & 3 <ul style="list-style-type: none"> Data Format Standards are also used in swimlanes 2 and 3 	Standard Setters Note (at top)... Add State Laws/Regulations	
Add line: col 1 <ul style="list-style-type: none"> Need to add line between Conduct Research and Aggregated Data in Master Database (Segment 4) 	How to Display These three statements were listed sequentially: <ul style="list-style-type: none"> Data flow goes reverse way. Communication the other way (may be there/mayn't be. Arrows should go both ways 	Add: col 2 <ul style="list-style-type: none"> Run Edits. This needs to be between Collect Data and Transmit data 	ADD: col 4 <ul style="list-style-type: none"> State Rules 	
Add: col2 → 1 <ul style="list-style-type: none"> Transmit Updated Data (from Hospital source to CCR) 		Add link Col 1&2 <ul style="list-style-type: none"> CCR and hosp registry collaborate in Research 	Add Activities col 2 <ul style="list-style-type: none"> Disseminate Cancer Information Conduct Research 	
Add Activities col 1 & 2 <ul style="list-style-type: none"> Processing Updates Quality Control activities Link between 		The Correct Errors nodes should connect to the Collect Data node, not the Transmit node, because the errors require data collection/correction	Add: col 4 <ul style="list-style-type: none"> Use Cancer Information Conduct Research 	

Pending task

Completed task

BUSINESS WORKFLOW ACTIVITY DIAGRAM				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
CCR and Hospital Registry on these activities		before transmission		
Add: col 1 at the top <ul style="list-style-type: none">Develop Rules and Standards		In the Non-Hospital swimlane, the data could be re-used		
		Should we treat consolidate arrow differently		

