

Requirements Findings

NPCR-MERP Hospital Strategic Assessment and Modeling Session
(SAMS)

Richmond, VA February 6th-8th 2006

CDC/DCPC/NPCR

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

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BACKGROUND ON NPCR-MERP

The Centers for Disease Control’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. Including 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 CDC.

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-Surveillance, Epidemiology, and End-Results Program (NCI/SEER), 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 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 registry
- Improve the completeness, timeliness, and quality of cancer data
- Reduce costs significantly – over time
- Reduce the amount of manual processes and make better use of CTRs’ time
- Improve data exchange between systems through use of industry standards

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SAM SESSION GOALS AND OBJECTIVES OVERVIEW

- **Project Approach**

Strategic Assessment Sessions

For each of the listed functions (Casefinding, Abstracting, Follow-up, and Editing/QA) of a hospital cancer registry, we carried out a series of team building exercises aimed at providing specific and detailed feedback on the following:

- Examples of acceptable or best practices to be duplicated 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 small group breakouts that were consolidated into successively larger groups until the entire group was reconvened to review and discuss the findings.

Each of these sessions was 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 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 was allowed to provide comments, suggestions, and also to express concerns or criticisms of each of the diagrams presented. The diagrams consisted

of the following:

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.

Hospital Use Case Diagram – A general overview of the core components of hospital cancer registry data flow. This diagram presented the highest level hospital-specific components that contribute to hospital cancer registry operations.

Hospital Context Diagram – Highest level view of the hospital cancer registry data flows. This diagram presented the highest level hospital-specific components that contribute to hospital cancer registry operations and their relationships.

Hospital Process Diagram – A high level summary of core functions related to cancer registry operations including case-finding, abstracting, and follow-up.

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

Data Element State Transition Diagram – A micro view of data migrating through the system from the original unstructured format initial state all the way to being electronically reported to the central cancer registry in an HL7 message.

Proposed Hospital Data Flow Diagram – An ideal data flow proposed as a result of an examination of Virginia Commonwealth University Health System (VCUHS) cancer registry operations.

The scribe and two recorders recorded each diagram review session and the comments were posted throughout the room on post-it sheets for continual display, review, and updating.

SESSION OUTLINE OF EVENTS

Monday evening, 7:00 – 9:00 pm

Introductions

Objectives Review

Top Opportunities for Electronic Registration

Monday evening, 9:00 – midnight (informal networking time)

Tuesday day, 8:30 – 5:00

Review MERP Core Diagrams

Detailed Examination of the Casefinding Function

- Vocabularies & Standards
- Key Story Selection
- Discuss and critique VCR/VCUHS models
- Odd, Problematic, Corner-case Situations
- Barriers to electronic delivery
- Pains & Payoffs
- What is Possible?

Summarize and Reflect

Tuesday evening (informal networking time)

Wednesday 8:30 – 5:00

Examination of the Abstracting, Follow-up, Editing/QA functions

Future Initiatives, Next Steps

Summary and Reflection

Wednesday evening (scheduled networking time)

STRATEGIC ASSESSMENT

Description of the Process and Methods for Casefinding:

Casefinding is generally described as “The systematic process of identifying all cases of a disease eligible to be included in the registry database for a defined population, such as patients of a hospital or residents of a state. It is also called case ascertainment” (See NPCR-MERP Glossary). Whether about the subject is active casefinding, passive casefinding, or some combination of the two, they all involve the cancer registrar or some other health professional seeking to identify potential cancer cases. This activity is crucial to calculating and maintaining accurate counts of cancer cases within any hospital. The NPCR-MERP Technical Development Team and the facilitator spent a great deal of time walking through this process in a step-by-step manner. In fact, the facilitator dedicated one full day to casefinding alone. This pace was designed to orientate the participants to the small group discussion format that would be repeated in other functional areas of follow-up, abstracting, and editing/QA. Subsequent sessions much shorter and abbreviated in time but equally significant in output. This would also allow for a tremendous amount of detailed information to be recorded that would later be available to the Technical Development Team for further analysis and review.

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

Casefinding Requirements Summary:

Casefinding stories described by the participants emphasized the presence of electronic casefinding in “good stories” and the lack of electronic casefinding in “bad stories”. Agreement on the need for promoting and implementing electronic casefinding (e-casefinding) seems to be established. Payoffs for implementing e-casefinding identified by the participants included real-time or early data for administration, business planning, and research opportunities, increased patient participation in treatment protocols, and will result in timely reporting to regional and state registries.

Several common issues came up in the Stories Development Exercises, the Odd/Problem Cases Exercises, and the Identification of Barriers Exercises that have an effect on successful e-casefinding implementation. Registrar issues encompass three themes:

- Registrar “buy-in” for e-casefinding
- Training
- Management support

The themes reflect the need for registrars to better understand both the rationale and the benefits of e-casefinding. Education and management support was frequently mentioned. Participants also felt that the increased time needed to process data from multiple sources would be a barrier to successful implementation of e-casefinding.

Throughout the SAM Session, participants discussed issues of IT support for revising current software, and the need to design and implement new software. Existence of multiple systems within a facility and frequent revisions to national data standards were serious concerns relating to IT issues. Financial concerns for e-casefinding were most often expressed when discussing software and standards issues.

Issues relating to access to data were minimal with concerns mainly for accessing ancillary hospital services data. Ongoing concerns regarding HIPAA-related requirements were also expressed.

Interestingly, the most frequent theme verbalized in the Odd/Problem Cases Exercise is only indirectly related to e-casefinding. This issue was determining whether the incoming record represents a reportable cancer or not. Associated with this problem are the repercussions of miscoded data resulting in missed cases.

Participants discussed what is possible in the next few years and what cancer registration will look like in five years.

There were two overriding themes in the five year projection for cancer registration: enhanced screening and enhanced software. In order to handle a significant increase in data sources queried and the number of records received, improvements in screening the records to identify reportable cancers are vital. A standard method for screening all data sources was an important concept. The most frequently cited enhancements were synoptic reporting and natural language processing functions. Auto-coding and assigning confidence level codes to electronic screening were specific suggestions to include in enhancing screening functions.

Software concepts appeared frequently in the five year projection scenario. Participants felt that there would be full acceptance of standards such as HL7, SNOMED and LOINC as well as secure connectivity between computer systems. Participants also mentioned buy-in by vendors, timely availability of software, and specific functions that would be useful to include in e-casefinding software modules.

There was only one theme on access to data sources and that was to have electronic extraction of data from multiple data sources. Accuracy was important so that no missed cases resulted. The need to have more complete information included in records from data sources was also an expressed need.

Participants identified new ways of doing business. Of particular note was the idea that once e-casefinding is established, this becomes the gateway to the rest of the electronic health record (EHR). One concept forwarded is the role of the central registry in e-casefinding. One participant projected that central cancer registries will have more oversight over hospital registries and that data from various sources could be synthesized into complete records at the central registry level in order to improve timeliness. This concept, along with improvements in e-casefinding by hospital registries, will further the development of real-time cancer reporting systems. Participants felt the concept of Regional Health Information Organization's (RHIO's) to be a useful concept in cancer registration; RHIO's may allow for remote access to multiple sources of data not currently available.

There were mixed opinions on whether e-casefinding would save time. Many felt a time savings could be achieved; however, there would be an increase in editing time to resolve data disparities amongst sources.

Possible Actions:

- Develop educational materials discussing e-casefinding and its rationale and benefits.
- Inform the appropriate standard setters that there is a need to develop educational materials for ancillary departments to emphasize the importance of sharing their information with the cancer registry.

- Refer the need to develop procedures for reviewing and using data from multiple data sources to appropriate standard setters.
- Refer reportability issues to appropriate standard setters for their review and possible resolution via expanded procedures and instructions.
- Develop standard messaging formats and data requirements for specific data sources (i.e., disease index, radiology, etc).
- Develop screening methods for specific data sources.
- Evaluate methods for increasing the use of synoptic reporting.
- Work with organizations currently developing natural language processing functions to increase their availability and use.
- Brainstorm ideas surrounding electronic record submission and processing timeline to improve the likelihood of developing correct concepts and models early in the process.
- Establish and disseminate e-casefinding standards and procedures well in advance of implementation to allow vendors sufficient time to modify and add to their software capabilities.
- Work with other organizations that have a stake or are currently working on e-reporting to ensure coordinated, standard and efficient practices.

Abstracting Requirements Summary:

Abstracting stories had common themes. The positive scenarios included the possibility that data could be pre-coded and inserted into registry abstract from multiple data sources. The Electronic Medical Record (EMR) is available for review. Remote abstracting is available in some places. The negative scenarios dealt with unavailability of information, including information only available at a non-accessible facility, information not being included in the medical record, and problems accessing the medical record.

Abstracting problems and barriers related to the process included incomplete data, conflicting standards, and frequent changes in standards. CTR related issues included changes in the work process, training for new procedures, changes in standards, and changes with traditional CTR required knowledge.

Participants were optimistic about the future abstracting environment. There were many specific recommendations for making electronic enhancements. Participants also felt that the electronic medical record (EMR) will positively affect abstracting.

Possible Actions:

- Collaborate with vendors to revise software to meet the new concept of abstracting
 - Real-time; no suspense file
 - Ad hoc entry of data as it becomes available
 - Multiple end-points to meet reporting timelines
 - Receipt of electronic data from multiple sources
 - “Review and approve” functions
- Monitor implementation of RHIO’s and their impact for cancer registries
- Collaborate with stakeholders to develop education and training materials
- Develop business rules for auto-coding and pre-loading data items.

Early Payoffs:

- Registry recognition
- Expanded research
- Complete studies
- Labor requirement reduction
- Timely, complete, and accurate data for hospital administrations and physicians to use
- Registry abstract actually used in planning future care

Follow-up Requirements Summary:

Follow-up stories had common themes. The positive scenarios all included having the data available when it is needed. Negative follow-up scenarios included finding out that the patient did not have cancer or that the patient did not meet the requirements for follow-up. The first situation is a public relations nightmare; the second situation is a waste of resources.

Follow-up is a manual and time-intensive process mainly due to issues surrounding access to data. Certain entities have the follow-up data but either cannot or choose not to share it with the hospital registry. Additionally, no established source for routinely obtaining follow-up data exists, and this requires registrars to make sequential requests for information from multiple data sources.

A related issue involves the accuracy of the data. Certain procedural tasks within the hospital can lead to misinterpreting a patient's vital status.

Possible Actions:

- Work with central registries to implement sharing of follow-up information

Editing/QA Requirements Summary:

Editing/QA stories had common themes. The positive scenarios all included having EDITS built into software. Having EDITS performed interactively was also mentioned. Negative scenarios dealt with lack of or poorly implemented EDITS in software, and conversions causing erroneous EDIT errors.

Participants rely heavily on EDITS to validate their data. Problems and barriers related more to the broad issues of CTR knowledge and skills, availability of the data to perform editing/QA, and documentation for EDITS software. Problems with EDITS itself were not mentioned. When discussing what is possible, however, participants focused almost exclusively on recommendations for improving the editing/QA process by enhancing EDITS.

Recommendations included enhancing EDITS with additional and more complex procedures, concurrent EDITS while abstracting, and improved documentation regarding EDITS definitions, rationales, and error correction, etc. EDITS need to be distributed in a more timely and efficient manner so that they are available when needed; obsolete EDITS sets cause data errors and use significant resources.

Possible Actions:

- Work with stakeholders to enhance EDITS as noted by participants.

- Prepare education and training modules on quality assurance activities beyond EDITS.

MODEL/DIAGRAM REVIEW SESSION

Description of the Process and Methods for Modeling Review Session

Each of the diagrams presented during the session followed to 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 of the diagrams presented during the session and the updated versions of each diagram.

Summary of participant recommendations stemming from the NPCR-MERP Hospital SAMS

- Develop a general process model that describes unified practice, supporting systems and standards
- Identify high payoff elements
- Make model available to vendors to allow for seamless integration with existing systems
- Communicate among and with vendors of health data systems (HITSP)
- Continue to include CTR's in model development
- Include small institutions
- Standardize and simplify procedures, including computerization where possible
- Communicate progress on the project: keep the registry community updated on a regular basis
- Break down political boundaries where possible

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

- Kickoff Web-conference is scheduled for March 28, 2006 at 2:30PM EST (call-in details to be provided).
- Work on developing the hospital 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 hospital systems around the nation to complete the hospital domain modeling effort and to create a report of guidelines and recommendations to advance the initiative.

APPENDIX A

Hospital SAMS Participant Response Summary Tables

CASEFINDING Process Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
Pharmacy unable to run chemo reports	Finding not in coding system	Who defines case reportability?	Increased editing of billing discharge/medical record coding to eliminate discrepancies	Registrars are unwilling to change current processes		working in available software		
Problems with filing system	Dependence on others to code correctly	Donors on list			e-casefinding	Vendor support		
		Collecting reportable squamous cell carcinoma				Vendor interface		
		Radiation for non-cancer patients						
		Recurrence versus new primary						
		Hematologist change system						
		Revised diagnosis						
		Consult only pathology; no way to report						
		Can't find case from regional registry						

CASEFINDING Organizational & Data Structure Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
Depending on others to provide information	Diagnosis of meningioma not giving behavior	Negative pathology diagnosis with a positive clinical diagnosis	Staff turnover need to retrain	Helping upper management to understand that electronic is better	Does it save money	Data in different fields	Systems that can't transport data	Standard setters don't have authority to mandate interfaces
Access to disease index	Mixed patient ID	Clinical with no other diagnosis	Why should hosp registrars care about regional casefinding	Registry management buy-in	Lack of funds x 6	Different software	Registry low on facilities list of IT priorities	
Outreach clinics	Odd cases site/histology	Easily missed tests for positive diagnosis	Data integration not trivial/consolidation from multiple sources	Registrar buy in	Funding in non-revenue generating department	Too much incoming inform that is not filtered or is not filtered	Networking issues	
Vital Status not available	Meaning depends on date/coding system	Imaging diagnosis only	Increase timeliness by synthesizing data sources of the state	Management support			Tiny interface looks big to IT bureaucracy	
Physician practices getting larger amounts of data		Sounds like cancer but isn't	Registrars	unaware of potential benefits of well-developed automated casefinding. Neither want nor request such a system				

CASEFINDING								
Organizational & Data Structure Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
Systems don't talk to each other		Capturing re-excision when the diagnosis is not cancer		Conservatism of profession/industry – resistance to change				
Hospitals don't like data mining from outside		Ambiguous terminology		Inertia				
		Treatment only, no background info		Lack of trust in e-system				
		Class of case 9; where did patient come from?		Admin resistance to new software				
		Consistent with/ (ambiguous terminology)		Skill set of r people receiving data				
		Small facility that uses outpatient services for emergency care		electronic knowledge or experience in the field				
		Positive core biopsy, negative prostatectomy. Positive urine, negative further	General	Training				

CASEFINDING								
Organizational & Data Structure Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
		workup						
		Histology of cancer is only mention of cancer						
		Conflicting information						
		don't have diagnosis date						

CASEFINDING Business Rule Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
Oncology doesn't want to send to registry, just to claims department	Miscoded x 2	Clinical diagnosis, not microscopic confirmation	How can casefinding be audited			Computer can't decide one or more primaries		Constantly change rules
Reason for radiation is not captured by system	Incorrect coding x2	New terminology new rules				Won't add function to send updates unless required		Overlap of standards
Can't use database, its mine	Incorrect coding on DC	Disagreement/confusion on reportability of certain cases						
You don't have HIPAA security x 4	Miscoded gender	Clinical diagnosis not agreeing with path.						
Pathology not reported		Decision on subsequent primaries						
Data security		"Our pathologist disagrees."						
Regulatory issues		Malignant to benign						
		conflicting terminology						

CASEFINDING				
What is Possible in Five Years?				
Access/Sources	Accuracy	Screening	Software/IT	New Ways of Doing Business
Adding sources to existing e-casefinding (disease index)	99% accuracy in casefinding sources	Screening will be ICDO3 based	NO technological barriers to anything we've discussed	Once e-casefinding gets going, it is the gateway to the rest of the EHR
Lots of different data sources; currently sent in electronically, but matching (patient linkage) is done manually	System with no missed cases	Automated pre-screening followed by manual review; improvements in pre-screening; more reports flagged for review; standardized review; Improvement in facilitating manual review phase	Buy-in of software vendors to have data come into the system	Time savings for registrars
Data extraction systems from different types of systems: imaging, chemotherapy	Demographic data on pathology report	More synoptics use; Buy-in for synoptic reporting; What people want is fully granular synoptic reports; Prototype to extract synoptic reports and put it into the registry	More vendors and suppliers will back software to tap into the hospital EHR	Registrars spend time editing billing, admitting, discharge, disease index data sent to registry
		Similar kinds of synoptic and SNOMED coding systems for other data sources	Simultaneous linkage of other data at the same time so we can compare different data sources	Move that will give central registries more power and scope over registries
		Standardize screening systems for different data sources	Software functions available when needed	E-path is used for reports from private path labs to the central registry
		Write a specific natural language processing specific to pathology reports. Would prioritize work, not replace it.	Secure connectivity between systems	Hospital system analyze information and send to two places - hospital registry, and regional/state registries

CASEFINDING				
What is Possible in Five Years?				
Access/Sources	Accuracy	Screening	Software/IT	New Ways of Doing Business
		Speech recognition software the pre-screening can be passed through they system without review.	Implementability: service-oriented architecture versus locally installed packaged applications	Increase timeliness by synthesizing data at state rather than hospital
		Auto-code site/type, behavior grade	Space for storing records in the facility registry	Further development of real-time cancer reporting systems
		Attach a level of confidence to the codes chosen by system	SNOMED free globally	RHIO's so there is regional reporting and then a linkage system to tie info from the same patients together
			HL7 Messaging	Centralized remote abstracting as the default model
			Standards will be HL7, SNOMED, LOINC for these two systems	Work with other organizations who are working on this type of initiative
			Customizable for other facilities where some sources aren't available	
			Maintain decisions so that registrar doesn't have to keep reviewing reports for cases already known to be non-reportable	

ABSTRACTING Process Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
Obtain treatment from outside facilities and not know which facility to get it from	Poor/incomplete medical record documentation		Lack of trained abstractors	Change in CTR work processes		Need to allow continuous flow of data over the months for concurrent abstracting		
Obtaining data from outside facilities			Skill speed of abstractor					
“Lost” dictation or late reports			Training not thoroughly completed before changes implemented					
Radiation therapy record not available at time of abstracting (separate department) but it contains all outside information			Learning curve					

ABSTRACTING								
Organizational & Data Structure Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
When is abstract “complete” if treatment can’t be located?	No treatment data	Ambiguity in the diagnoses			Staff/budget cuts		Implementing EMR	
	How to identify if surgery is for cancer (example: incidental appendectomy) ?	Multiple reports with different histologies						

ABSTRACTING Business Rule Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
	Lots of data items with specific coding rules; creating abstract from electronic may never be possible.	Conflicting Demographics	You must make “common sense” decisions about case					Conflicting rules or standards
	Changes in coding, staging rules	Need logic for some primary sites	Lack of routine method to know what to look for given what is already known about the case					Lack of knowledge about standard treatment protocols
	Complexity of business...rules for consolidation from multiple sources	How to distinguish ancillary drugs from chemotherapy drugs						
	How to identify/code new treatments							
	What is endpoint? When is case complete?							

ABSTRACTING				
What is Possible in Five Years?				
Access/Sources	Accuracy	Screening	Software/IT	New Ways of Doing Business
Standardized Pathology reports	Consistency check on entry into system	Possible auto-population of some core data fields like demographics, treatment and staging (Electronic acquisition commencing with demo, cap data elements, treatment, outcome)	Standardized Vendor software	Everyone have the same standardized business rules
Data readily available from other facilities		Embody synoptic path for lab values, Radiation therapy, chemo agents, surgery, radiology	Electronic access to EMR	RHIO will be more visible; abstracting easier if MD enters into RHIO and hospital and central registry can get data
Accurate/complete data/records		Reduce time to abstract; review of pre-entered data, rather than manually abstracting Remote abstracting	Text will all be cut and paste based on auto-highlighting of certain terms selected by the software	Recognition of text blocks will help in getting other data items pre-loaded into system
			Spell checker in text fields	Build abstract as information is acquired – not residing in suspense
			Facilitate automatic email for additional information from MD's and other registrars	Much more outsourcing of CTRS, not seen as part of hospital system (bad)
			Two monitors for review of records while abstracting	

FOLLOW-UP Process Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
Late posting of charges		Physicians, patients do not respond	Time – gets put off to last	Change in CTR work processes, learning curve				HIPAA/Consent
Social worker can enter note in EMR after patient dies								

FOLLOW-UP								
Organizational & Data Structure Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
State sharing with hospital					Cost to link with national databases	Some state registries are incidence registry and don't include follow-up data	IS (IT Staff at facility)	
Global society								
Losing patients								
Hospitals without a registry do not collect/maintain follow-up data								

FOLLOW-UP								
Business Rule Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
		Correction of death status...Marked as having died on error						
		How to decide on disease status						

FOLLOW-UP				
What is Possible in Five Years?				
<i>Access/Sources</i>	<i>Accuracy</i>	<i>Screening</i>	<i>Software/IT</i>	<i>New Ways of Doing Business</i>
Follow-up data is obtained from sources not currently available to registrars	SSN is key to linkage	Shared follow-up from state registry	Automatic sharing of follow-up between facilities	Networks of RHIO's cooperate with registries
Patient data bank to be used US-wide		Total linkage and downloads for automatic update	Voluntary cross-enterprise patient ID (by subscription offered by registries)	

EDITING/QA Process Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
						No running edits program running on software while abstracting	Real-time cross-enterprise data browsing does not exist	

EDITING/QA Organizational & Data Structures								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
Outside data is not always in record to review	Limited cross mappings from CS to SNOMED, ICD, IDCO3		Skill set of QA reviewer	Change in CTR work processes; learning curve		Computer problems		
State registry does not have source documentation to review when consolidating cases from hospitals			Time – registries are behind; time to learn	Don't think there will be as much resistance to this change as is commonly thought.	Vendors	haven't done a good enough job in getting editing/QA functions in software		
			CTR exam is too easy because education is not required	The turnover rate hasn't been factored in... There are many new faces and then are gone.				
			Employees that pass the exam should continually code	Younger CTR's are resistant to change because of workload. With the 6month time				

EDITING/QA Organizational & Data Structures								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
				rule, they are afraid of having to slow down for learning and then missing the deadline.				
			Education level of staff performing the edit process	Board of NCRA is concerned about the how the registrars react to change				
			Knowledge and experience of registrars	Training is an issue; hospitals need to pay to have the registrar get the training he/she needs				

EDITING/QA Business Rule Issues								
Access to Data	Coding Problems	Problematic Areas of Reportability	CTR Issues	Resistance to Change	Financial	Registry Software Issues	IT Issues	Standardization
							National/state edit is wrong so can't pass	
							Lack of user friendly edits documentation	

EDITING/QA What is Possible in Five Years?				
Access/Sources	Accuracy	Screening	Software/IT	New Ways of Doing Business
Electronic process for physician review – maybe reimbursable (CPT code assigned)	Necessary algorithms released to software vendors in advance to implement changes to provide for concurrent abstracting	Single screen editing versus volumes of paper	All software programs will have concurrent edits	Other QA like intermittent lists of usual problems; canned reports for QA; include abstractor and date
	Edits provided to software vendors in advance so QA can be done at time of abstracting		More edits and more comprehensive editing getting rid of editing fields that are no longer collectible	QC flag based on treatment guidelines to see if something is missing; warning flags based on stage and site
	Standardization of program partner edits and distributed in a timely manner		Windows based version of genedits	Edits based on checking data fields and stage match (tumor size, nodes, etc)
	Automatic distribution of corrected or updated edit		Extend logic of complex edits to include other fields (e.g. collaborative stage)	If concurrent abstracting can use abstract at Cancer Conference for physician review and editing
	Still need visual review for accuracy; can't eliminate it		Each edit produces a complete explanation of error and how to fix it.	More automation of visual QC using text mining
			Real-time interactive edits during abstracting, with documentation	Produce an audit report on demand per abstractor, after abstracts was thought to be complete
			Computer programs that do better job with edits than people	Automatic tracking of timeliness; also of timing for finding follow-up/update information.

APPENDIX B

Modeling Session Participant Comments, Suggestions, and Updated Diagrams

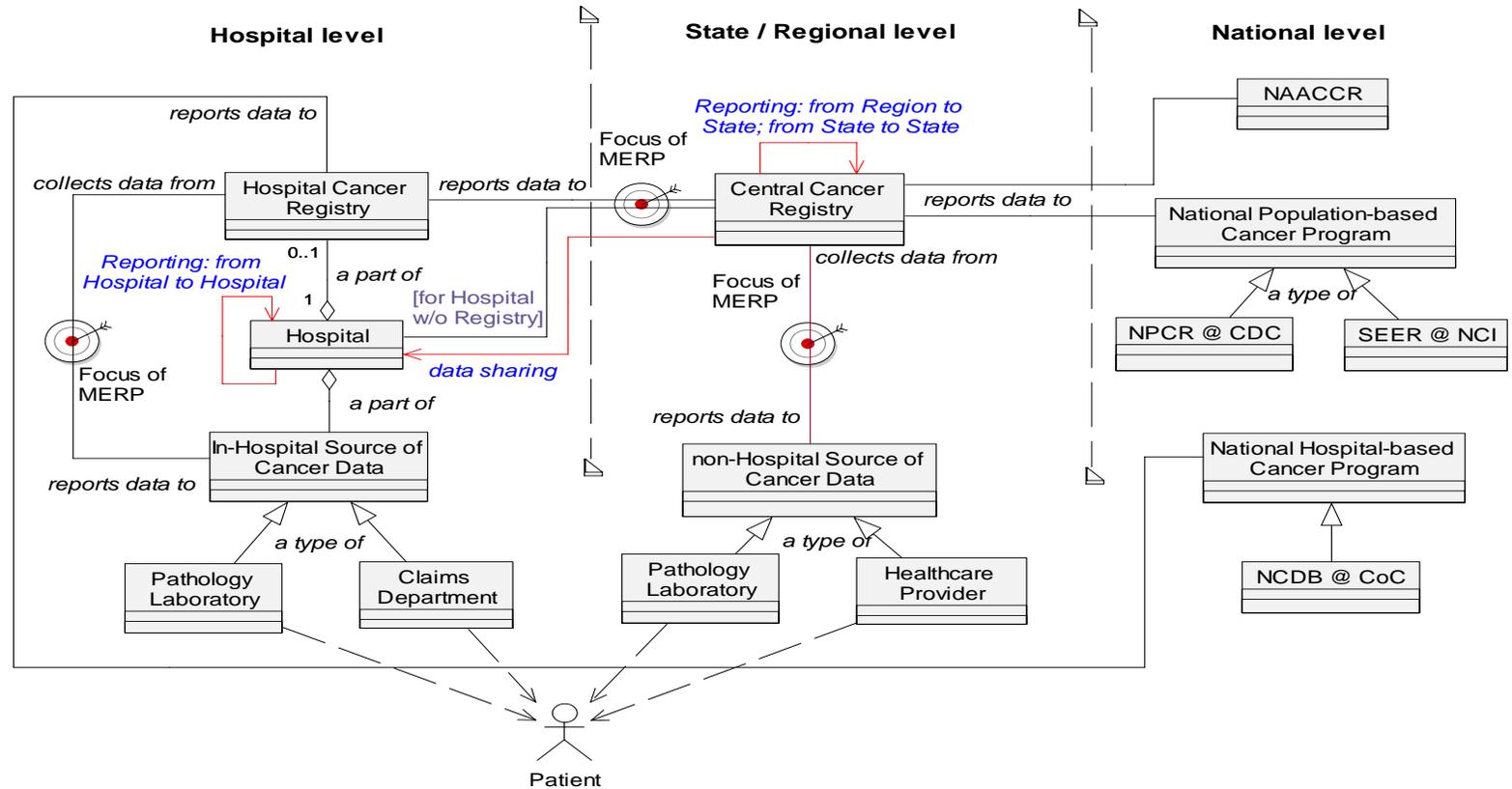
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Pending task

CONTEXT DIAGRAM				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
		Registries may report to multiple national registries	There is a regional level as well. Need to add a fourth level in some states...Regional also submits to the national areas; A matter of power and control.	Sharing of data...Trickle down, in addition to trickle up. Some hospitals won't share because of HIPAA considerations.
		May have a hospital consortium; one registry for multiple hospitals. May need to add a second level of hospital showing the consortium	Screening data	Don't want to restrict the diagram to just to state trickle down. Need national trickle down.
		Data flow from hospital to other departments in the hospital	Clinical data	State rules and regulations can play a part in returning data
			Quality control feedback	Add state-to-state sharing of data
			Private pathology labs within the hospital	Hospitals need to get data from sources that are currently under the central registry role
			Physician offices info is needed; who is allowed to give this data to whom: who owns what?	

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
 NCI: National Cancer Institute
 NPCR: National Program of Cancer Registries
 SEER: Surveillance, Epidemiology, and End Results Program

Completed task

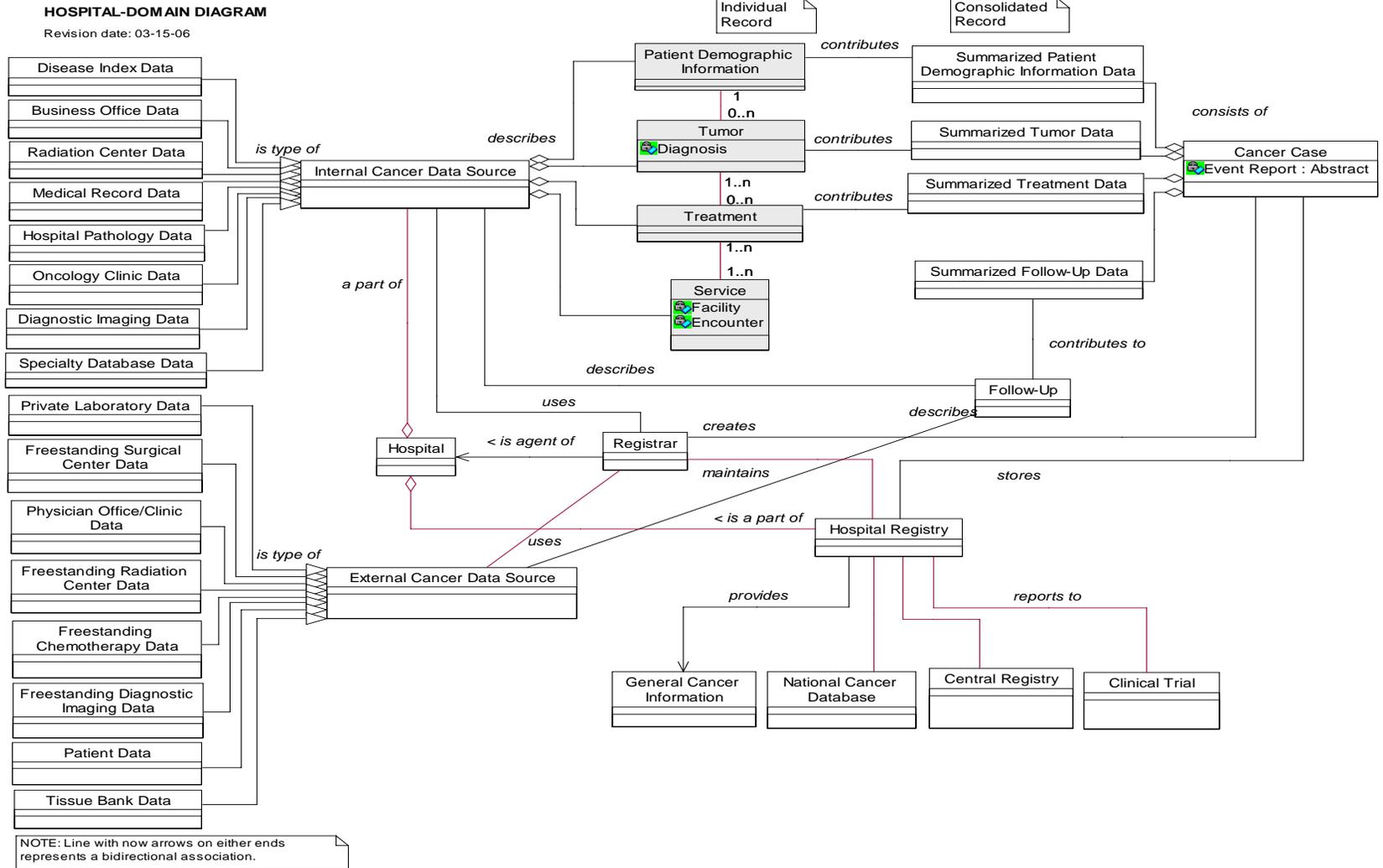
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HOSPITAL DOMAIN DIAGRAM				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
Employee change name to “agent”	Was impressed with diagrams	Need to make direction of hospital to x and x to hospital more obviously clear. Make it explicit by line up and line down	Consider tie in to tissue bank	Data integrity is important. Who takes ownership?
Radiology facilities; internal and external		Other database: like large breast cancer databases within the hospital	Tie into the RHIO’s Hospital will be a data source and a recipient	Quality control activities: internal and external; managing feedback from external sources
Use patient as a resource		Try to standardize how we segment parts of the patient record so that we call them the same things throughout all of the diagrams and text. Consider the current naming of patient record	Hospital registry is only involved if there is rapid ascertainment	Hard to find out which patients are on clinical trials. Only way to find out is that the MD documents in the chart. Need to find some way to get the information from a clinical trial back to the small community hospital
Need to reverse the arrow so that central registry reports back to hospital with information				Question about addendums and supplemental reports. Need to get these matched up to the original electronic path report
Make sure clinical trials can report to registry and registry reports to clinical trials				Breakthrough use cases from Brailer: physician to physician data. ONCHIT may propose

Completed task

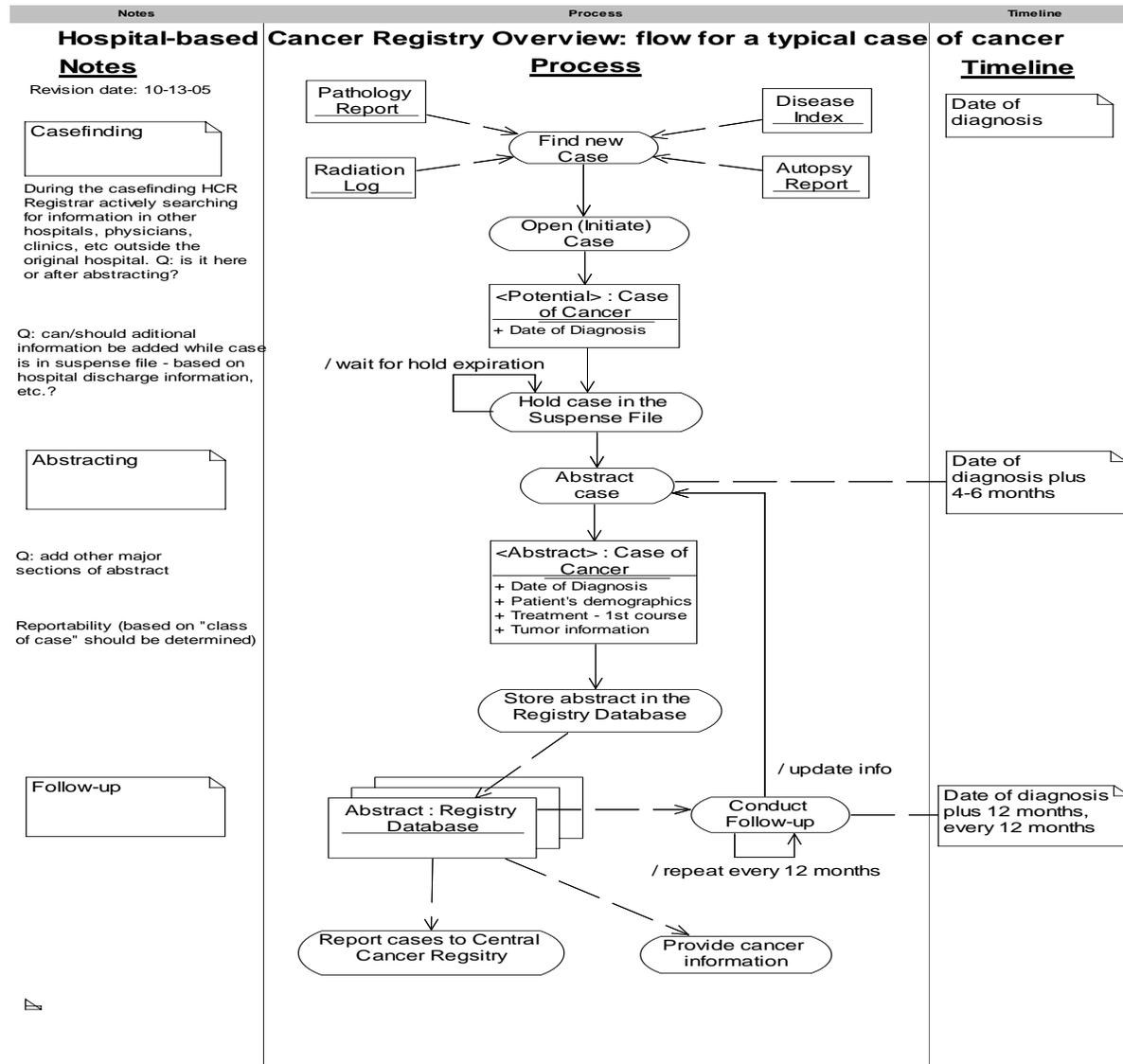
Pending task

HOSPITAL DOMAIN DIAGRAM				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
				solution to integrate unity amongst patients across the country
Some hospitals need to report to a second central cancer registry. Develop a terminology that describes the relationship				



HOSPITAL PROCESS DIAGRAM (GENERAL)				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
Add data editing		Potential case of cancer: do we have this case already?	Protocol accrual list	A problem if central registry doesn't take automatic updates
		Abstract case of cancer: make these details consistent amongst diagrams Use specific terms for case and abstracts consistently		Big area for improving timeliness; help define triggers. Will be a lot better off
		Do we need place that shows when it isn't a case?		
		Reporting to cancer registry. Looks like it is 12 months. Needs to be placed better in the diagram		
		Is it reportable, do I already have it?		
		Case finding and getting cases reported. There should be some indication that others are responsible for providing cases		
		Completion of an abstract; its akin to a signed pathologist. Need to have a specific identification of the completion of a case		
		Worried about suspense file. Lots of valuable		

HOSPITAL PROCESS DIAGRAM (GENERAL)				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
		information prior to the end of a full complete case. Suggest a first completion when activities in your hospital cease. Want to label specific points. Abstract a couple days after discharge. Want a definite date for when case is complete and not waiting for another piece of information to come in.		
		Needs to be an end point for every event		
		No standard for defining a case as complete		



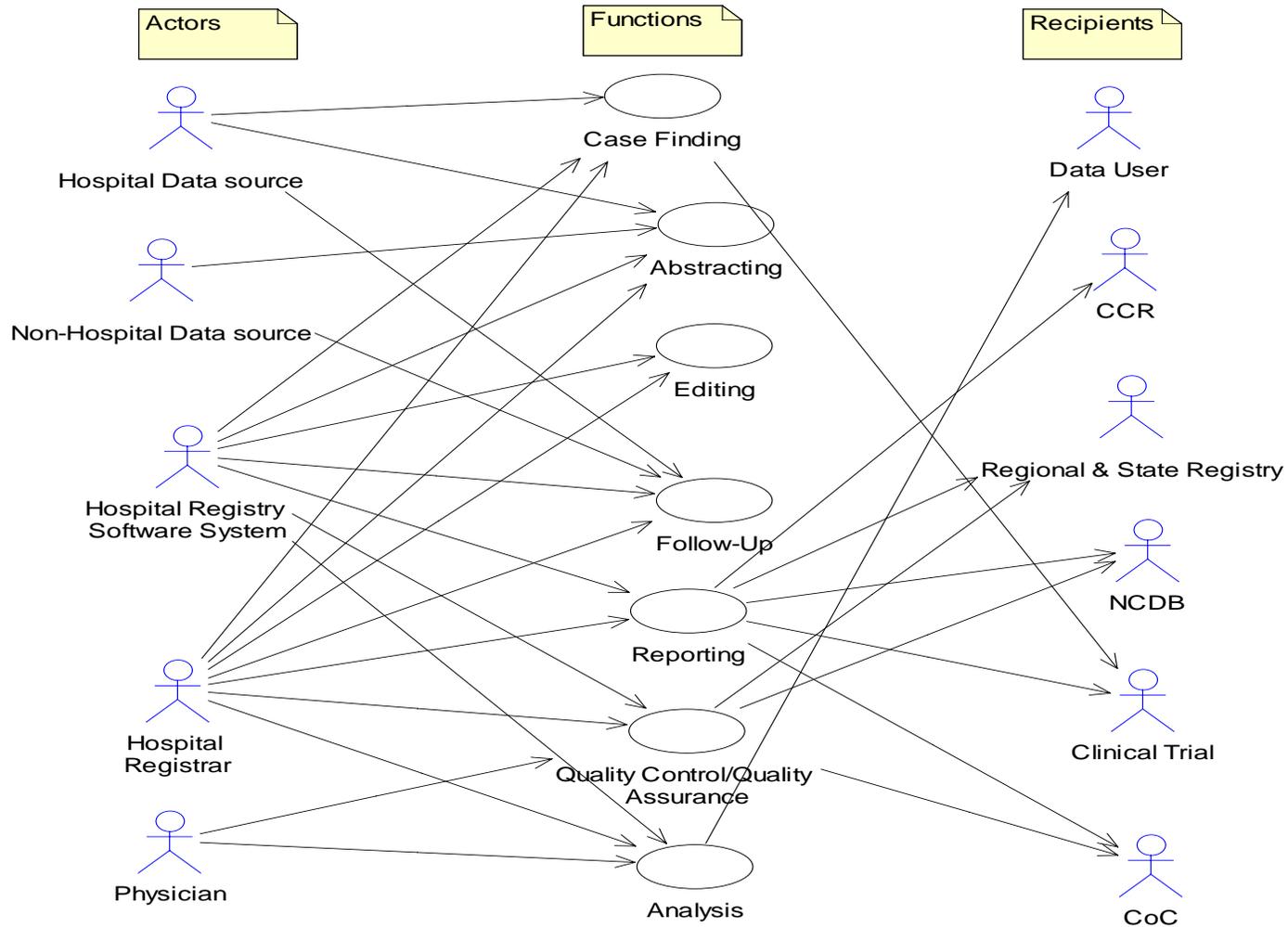
Completed task

Pending task

HOSPITAL USE CASE DIAGRAM				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
Other QC activities		Analyzing and preparing reports	Doesn't link in with other diagrams	There is are annual changes to the disease index
Another actor; medical staff		Correcting, deleting and canceling reports	Show major activities from process diagram and who is involved in the activities. It is a table of contents for the future work	
Do we need to add hospital data source and hospital registry software link?				

NPCR-MERP Hospital Use Case Diagram

Revised 03-15-06



PROPOSED HOSPITAL PROCESS DIAGRAM (PROPOSED DATA FLOW BASED ON VCU CANCER REGISTRY OPERATIONS)				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
There has to be a QC process before actual NCDB	Flip the third column with the fourth column then everything would fall into place	Suspense work waiting to be done. What is the suspense file?	Don't want the registrar to query, treatment information is different and can be done by the abstracter	Triggers can be determined if you are abstracting concurrently
Patient would be considered lost if follow-up is done late. reporting is once in 12 months ...complete abstracting should be done within 6 months of contact with your institution	Mistake to draw lines across as all happens simultaneously....the report to the state and NCDB are calendar based	When you query the system does it automatically update the system? That should be the first follow-up	The generating reports for NCDB and....out of place and they are a separate set of activities and it doesn't show internal data usage and also follow up information and correction and feedback reports should be a part of follow up activity	Somewhere in the process ...trigger should be for the registrar to say that it should go for rapid reporting...second trigger...when the case is actually complete and then the system automatically flag to warn that the case should be finished
The way the run edits shown would it incorporate interactive edits	Move the computer request for information action line above the registrar request for information action line. (even though horizontal lines do not have a chronology meaning, the participants would prefer to see the computer request.... action shown first.)	Triggers that can show timing		Follow-up would be done once a year but you need to know the duration that patient is not seen to schedule a follow-up
	The top section should be iterative	Arrow from a case finding report registry at this point the data is for		Since most of our state require to transfer case...the text code or

PROPOSED HOSPITAL PROCESS DIAGRAM (PROPOSED DATA FLOW BASED ON VCU CANCER REGISTRY OPERATIONS)				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
		follow-up if the update are done simultaneously and the date of last contact never gets to be 10-15 months late then you will not require follow-up...follow-up gets generated for those patient		message that says that treatment will happen sometime later...so you get correction record
		It should be an immediate send to the state...extra delay		How to QC negatives
		Is HL7 being used?... Standard report to CR is in the NAACCR format rather than HL 7 format...if the CRR is able to provide follow up to hospital then they don't need to do it so it saves them a whole lot of time and effort		What is the stop point? What happens to them? The results are stored... Add as QA steps
		Site codes and histology with edits right in database. Pull in rules for multiple primaries to have system decide		The concept of pooling is a process issue
		Not clear why update case doesn't go into abstract case once information comes doesn't it go to abstract		A registry is going to have a comfort level for when they can release a record for rapid reporting. May want to have one pass

PROPOSED HOSPITAL PROCESS DIAGRAM (PROPOSED DATA FLOW BASED ON VCU CANCER REGISTRY OPERATIONS)				
Content Issues	Appearance Issues	Clarity/Precision Issues	Scope Issues	Other
		case instead of going down		through before we send the record, but not until every little piece is available and fully edited
		Would you have a line coming from the top to information coming from abstract? when next piece of information comes, there should be a box at the top which says that there should be an abstract initiated at the top to alert you that you have next piece of information without query		
		The suspense file- ways to put things into suspense no way to take out there has to be a process to do that		
		Two activities to follow-up...is it redundancy or the process		

