A Human-Centered Information System

for Central Cancer Registries

In Brief

Central cancer registries (CCRs) collect, consolidate, and support cancer patient data from reporting facilities. Selecting and/or upgrading an information system suitable for central cancer registry work can be a complex process. Employing a human-centered approach that takes into account the needs of cancer registry staff can help significantly in these efforts. Here is how our researchers used a human-centered approach to evaluate a cancer data management system as it was being implemented for use by the Missouri Cancer Registry (MCR). Other organizations can use the MCR experience as a guideline or model for evaluating a central cancer registry software program.

Data collected by central cancer registries help clinicians understand and address the cancer burden more effectively.[1] Information about cancer incidence and survival is, in fact, vital to preventing and treating the spectrum of diseases called "cancer"—diseases that nearly one in two men and more than one and three women in the United States have a lifetime risk of acquiring.[2] Cancer data are processed at three, sometimes four, levels: national, state, regional (in states with regional registries), and at reporting facilities. For example, the Centers for Disease Control and Prevention (CDC), through the National Program of Cancer Registries (NPCR), provides support to CCRs.[3,4] Specifically, CDC/NPCR-funded cancer registries:

- Provide high-quality data that can be used to determine the impact of cancer on a statewide level
- Examine trends in cancer incidence (e.g., by site or demographic characteristic)
- Assess the burden on specific populations (e.g., by gender, race/ethnicity, and geographic location)
- Evaluate prevention and control efforts.

Without complete and accurate data, developing effective comprehensive cancer prevention and control programs for both state and national levels would be difficult—if not impossible.[5]

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About the Missouri Cancer Registry

In Missouri, the Missouri Cancer Registry collects, analyzes, disseminates, and interprets cancer incidence data. Reporting of cancer cases to the Missouri Department of Health (now the Missouri Department of Health and Senior Services) for Missouri hospitals became mandatory in 1984 after legislation passed by the State General Assembly. When more and more cancer patients began receiving treatment outside of the hospital setting, legislation passed in 1999 required pathology laboratories, ambulatory surgery centers, freestanding cancer centers and treatment centers, physician offices, and long-term care facilities to also report cancer cases.[6] Today, the MCR works with these facilities to acquire all reportable cancer cases in the state.

Since 1984, the MCR has gone through several upgrades to its data management systems. Each upgrade brought about enormous changes in terms of operating systems, databases, system functionality, usability, and more. In the process, the MCR identified some basic features that its data management system should possess in order for its certified tumor registrars (CTRs) to successfully, completely, and accurately process data. Many of these features employ a "human-centered" approach, where the software meets the needs of its cancer registrars and program administrators—and not just its programmers. Here's how the researchers identified methods to employ the "human-centered" approach, using MCR's experience as a real-world example.

Study Methodology

Guided by human-centered design principles, our researchers employed the following four methods:

1. Semi-structured interviews
2. Training material review
3. Focus group of key MCR users
4. Teleconferences between software developers and users.

The Semi-structured Interview. Prior to these interviews, group meetings were held to discuss issues such as system installation, migration and conversion of data, and data consolidation. Researchers used the information gathered at these group meetings to prepare interview questions based on

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the principles of human-centered distributed information design (HCDID).

HCDID incorporates the theory of distributed cognition with the need for four major levels of analyses in system design: 1) user analysis, 2) functional analysis, 3) task analysis, and 4) representational analysis. This method identifies human and artificial agents as two indispensable components of a single distributed system. In contrast to computer systems based on engineering and technology principles, HCDID integrates human-computer interaction, interface design, and human factors—all of which significantly contribute to ease of learning and ease of use. HCDID proposes that systems should include *only* the necessary and sufficient features and/or functions that match user capacity and are required by the task.[7]

The semi-structured interviews were conducted during the first two weeks of implementing the MCR's new data management system. During these interviews, researchers acquired information related to user capacity and experience. Interview questions covered four areas:

1. The user's personal background in cancer registry work. *How long have you worked in cancer registry or an associated field? How do you evaluate your computer skills using general software applications such as MS Windows, Office Suite, Database, etc?*
2. The user's experience or impression of the data management system upgrades. *How many hours on average did you spend on learning a new data management system? How do you familiarize yourself with new information systems? Have you tried other learning methods outside of the traditional ones such as group and personal training, self-study on user manuals, and consulting experts or other users?*
3. The user's typical routine tasks and workflow with special emphasis on quality assurance (QA) and data submission steps.
4. The user's preference on system features, such as print preview, progress bar, help menus, and more.

After these interviews, researchers mapped the information together, and identified the basic system tasks needed for users to successfully complete their routine work. The end result: a list of design requirements for the ideal human-centered information data system.

Review of User Training Materials and a System Demo. Researchers next reviewed training guides,[8-10] user manuals,[11-14] online help, and other information. In addition, researchers demoed the new system using a version that contained a limited number of sample abstract reports.

Focus Group. In addition to interviewing staff in the QA unit where many key components of the information data system are used, researchers also conducted a focus group discussion to acquire supplementary information such as system usage, maintenance, and user feedback to developers. The focus group was comprised of database managers; center administrators; reporting coordinators; and coding, review, and follow-back specialists. The focus group discussed system user concerns regarding:

- Installing the new information data system
- Importing electronic records
- Editing data and consolidating cases
- Maintaining database integrity and security
- Extracting files
- Using report-generating capabilities.

Data Management System Specifications Necessary for Cancer Registry Work

Central cancer registries provide, support, and update standards and system changes for their reporting facilities. Our own experience and published literature[1] has helped us identify 10 data management system specifications that should be made available to the user:

1. Data sets that conform to established industry standards
2. Quality assurance (QA) components that can be audited
3. System backup and restoration capabilities
4. Statistical programs (e.g., SEER*Stat, SAS) supporting local population-based reporting requirements
5. Flexibility on special features customizable to unique requirements and data formats
6. Reporting requirements compliant with national criteria
7. Data transmission requirements on hardware, network, etc.
8. A mechanism for capturing system errors during user operation
9. Readily available technical support
10. A transparent timeline for implementation and system upgrades.

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Teleconference with Developers. Researchers participated in weekly teleconferences between the MCR and the development team discussing data migration, data conversion, and system installation issues. Two critical takeaway messages: communication is vital to a data information system implemented in a real-work setting and users are expected to maintain the data on their own. In addition, these teleconferences underscored the importance of user involvement before, during, and after the data information system design process.

The next step was to analyze the information gleaned from these four research methodologies. Once again employing HCDID techniques, researchers were then able to identify three key elements for a human-centered design of the data management system: user characteristics, CTR tasks, and representations of data management.

User Characteristics

The majority of users of cancer data management systems are certified tumor registrars. Earning the title of CTR is not an easy process. To be successful in the cancer registry field, individuals must obtain a strong background in:[15]

- Anatomy and physiology
- Medical terminology
- Medical record management
- Confidentiality rules and regulations
- Communication skills
- Computer applications and database management skills
- Statistics and business management.

In addition to the knowledge and skills listed above, CTRs must also be proficient in computers and data management. The cancer data management system you select will play an important role in the success of your cancer registry; however, the system only supports basic and necessary tasks. Other essential tasks, such as effective communication between your cancer registry and reporting facilities, state agencies, and national organizations, are generally supported by other software applications and hardware technologies. In other words, while CTRs may not be required to be computer "experts," some knowledge of the Windows operating system and MS Office Suite (e.g., Word, Access, Excel, etc.) is considered a basic requirement.

Lucid, effective communication is also essential. In fact, effective communication skills are the foundation on which high-quality cancer incidence data are collected and managed. Communication skills include but are not limited to:

- Face-to-face conversations that can occur during group meetings, conferences, and/or professional workshops
- Technology-mediated conversations (e.g., phone calls, emails, Webinars, etc).

Beyond basic communication skills, it is vital for CTRs to be able to capture, describe, and reproduce problems related to the data information system. There is no perfect data information system; however, user feedback helps the developers of cancer registry data management systems to improve their products. This feedback can occur at all levels of computer proficiency.

CTR Tasks

According to the National Cancer Registrars Association (NCRA), cancer registration involves collection, management, and analysis of cancer incidence data for seven purposes:[15]

1. Research
2. Quality management and improvement
3. Cancer program development
4. Cancer prevention and surveillance
5. Survival and outcome data
6. Compliance of reporting standards
7. Development of accreditation standards for cancer registration.

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CTRs perform a number of routine tasks using data management systems. These tasks are based on collaboration and coordination and are generally carried out in step order.

First, the CTR uses standard data items and codes to abstract and code cancer cases. As a state central registry, the MCR is responsible for collecting abstract reports of cancer from all sources, including hospitals, freestanding cancer centers, pathology labs, and physician offices. Low-volume facilities may submit data via paper charts or forms. Other facilities submit data through web-based applications, which allows our CTRs to upload data files in a NAACCR (North American Association for Central Cancer Registries) format.

Second, CTRs process, review, and edit reported abstracts. Data must be checked for completeness and accuracy before records are ready for consolidation and linkage to central cancer registries

The third step is for the CCR to consolidate multiple reports into incidence records based on the information of patients and tumors. Data management systems support this consolidation by processing edits. This automatic process employs a probabilistic reasoning approach, linking records by detecting duplicates within the registry to reduce overcounting of cancers. CTR participation is mandatory to better determine multiple primary tumors and merge data items from multiple case reports into incidence records. While data management systems can automatically process most abstract reports that pass edits, CTRs examine data in a variety of ways to guarantee the quality and consistency of the cancer registry process.

CCRs publish statewide and local-level population-based statistics of cancer incidence and report periodically to NAACCR, CDC's NPCR, and/or the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) program. NPCR and SEER jointly publish national population-based statistics on cancer incidence and mortality.[3]

A human-centered data information system must take

Table 1. Registry Plus™ Suite of Software Programs[1]

Product	Function and Use
Abstract Plus	■ Used to abstract and code cancer cases using standard data items and codes ■ Customized by central registries for distribution to and use by hospitals and other reporting sources to abstract reports of cancer ■ Also used for special projects and start-up registries
Web Plus	■ Used to abstract, code, and collect cancer data securely over the Internet ■ Customized by central registries for abstracting and reporting of cancer by physician offices, low-volume facilities, and for follow-back efforts aimed at increased cancer reporting ■ Supports upload of files of abstracts in NAACCR format; used by hospitals and non-hospital reporting sources for submission of files of cancer reports to central registries ■ Eliminates need to distribute and maintain software at reporting facilities
Prep Plus	■ Used to receive and apply data quality and completeness edits to batches of abstracts ■ Customized by central registries for processing, reviewing, and editing reported abstracts
CRS Plus (including TLC Plus)[2]	■ Used to link and consolidate edited abstracts in the central registry ■ Customized by central registries for creating consolidated patient and tumor tables for the same person and tumor with the best values from multiple sources ■ Provides for automatic determination of multiple primary tumors and consolidation of data items from multiple case reports into incidence records ■ Produces extracts for NPCR and NAACCR call-for-data submission ■ Provides standard management reports
Link Plus	■ Uses probabilistic methods to link records ■ Configured by central registries for: • Detecting duplicates within the registry to reduce over-counting of cancers • Linking cancer registry files to external files for follow-back and purposes research
Registry Plus Online Help	■ Used to look-up abstraction and coding information ■ Contains current versions of all standard abstracting and coding manuals (NAACCR, FORDS, CS, ICD-O-3, SEER, and ROADS) ■ Facilitates abstraction by centralizing information into one easy-to-use resource ■ Eliminates need to purchase and maintain manuals in hardcopy form

[1]Registry Plus™, a suite of publicly available software programs for collecting and processing cancer registry data. Atlanta (Ga.) U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion; 2005. Available online at: *www.cdc.gov/cancer/npcr*. Last accessed February 11, 2008.
[2]CRS: Central Registry System, TLC: Tumor Linkage and Consolidation
Source: Reproduced from *Steps Towards Conversion to Registry Plus*; 2007. Available online at: *www.cdc.gov.cancer.npcr*.

into account all of the tasks outlined above and support all the functions required to effectively carry out these tasks. In addition, as no one data management system offers every function needed by reporting facilities and central cancer registries, interoperability between different types of systems is of key importance during design and implementation. Data sets in any cancer registry system must conform to established industry standards, such as NAACCR record layout and coding schemas.

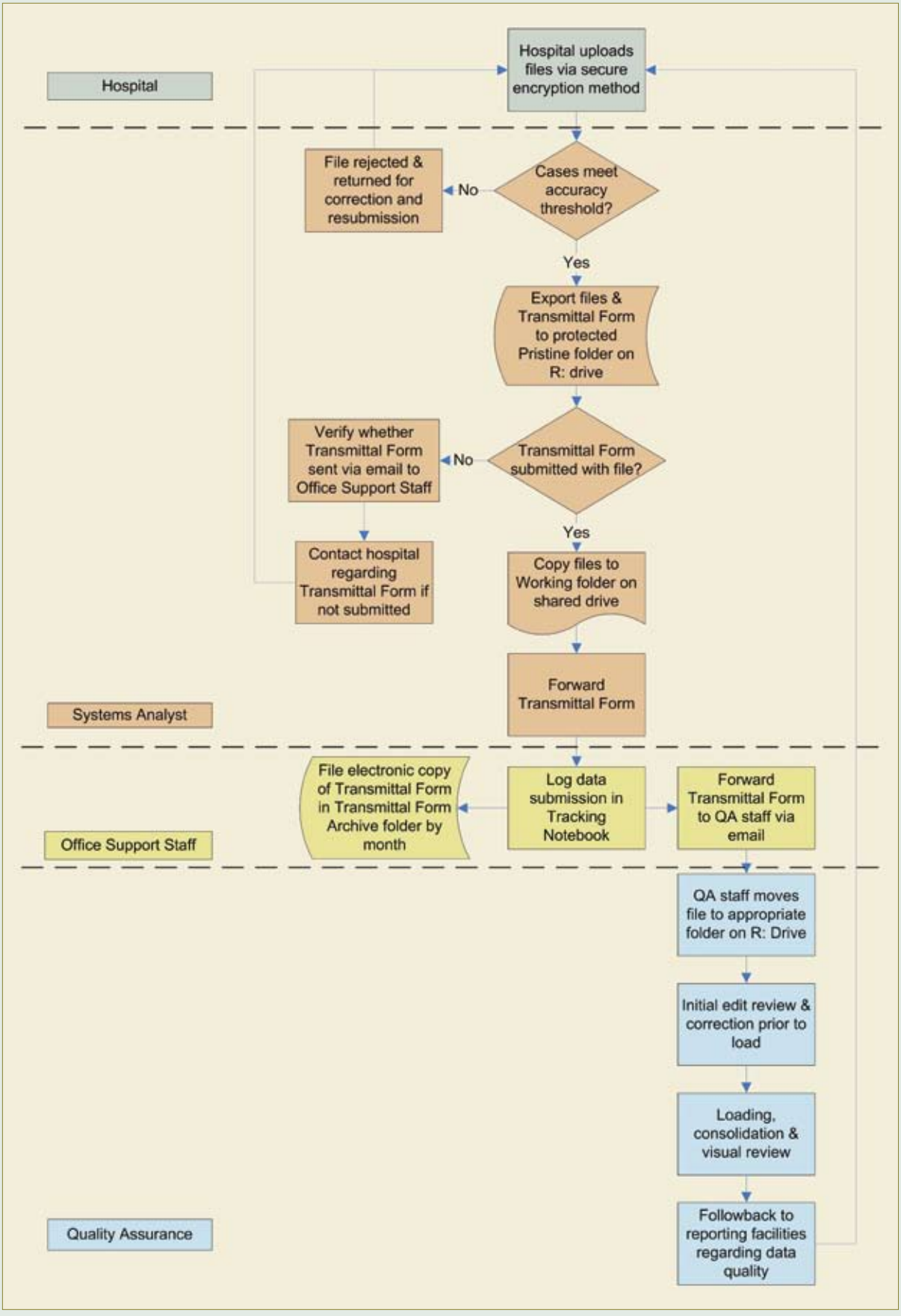
As a central registry, the MCR provides, supports, and updates standards and system changes for its reporting facilities. Our own experience—and published literature[16]—has helped us identify data management system specifications that should be made available to the user (see box on page 31). Table 1 is an example of a suite of software programs, publicly available for free, for collecting and processing cancer registry data. The Registry Plus™ software can be used separately or together for routine or special data collection. These software programs, compliant with national standards, are made available by CDC to implement the National Program of Cancer Registries. Figure 1 is a flowchart of the cancer registry data process. This flowchart uses an Internet-based management system; support communications, such as email and telephone communications; and requires coordination between different groups and facilities.

Data Representation

Consistency and standardization are vital in cancer registry work—not only in abstract reporting but also in data management system design. While abstract reports should conform to national and state standards, there are no established "standards" for data management systems.

As a general rule of thumb, users should not have to guess whether different words, situations, or actions have the same meaning. For example, when naming a button which ends a task and keeps the results, data management system

Figure 1. Flowchart of Cancer Registry Data Process



designers should be consistent and avoid using multiple words, such as "Save," "Okay," and "Confirm," to explain the same action. Functionality should follow common sense or conventions but be consistent in any system design. Users expect consistency in other areas including:

- Sequences of actions (skill acquisition)
- Color schema (categorization)
- Layout and position (spatial consistency)
- Font usage
- Graphic design.

Frequently, CCR staff want information about the status of the data management system or the status of datasets being processed by the system. Human-centered data management designs allow for visibility of the system at all times. Users know what is going on with the data management system through appropriate feedback and display of information. For example, a progress bar during dataset processing allows users to predict the outcome and estimate time required for the job. Bottom line: visibility is a key design feature that also increases work efficiency.

No matter which data management system you select, users should receive prompt and informative feedback about their actions. This feedback should be concrete and specific so that users can directly perceive, interpret, and evaluate their actions. Although error messages such as, "system error, code 105" or "illegal action" may be good for program developers, they do not offer users adequate information. In fact, users may not even understand error messages that are too abstract. Instead, developers should use clear, precise, and constructive language and avoid obscure, vague, and general codes.[17]

User control is another component of human-centered data management systems. Users that believe they are being "controlled" by the system and not able to do exactly what they want become easily frustrated. In a human-centered system, users are always the initiators of actions—seldom, if ever, the responders to actions. User-friendly feedback and visibility offers this type of control, as well as allowing users to schedule their tasks in advance.

Human-centered data management system design should take into consideration both novice and experienced users. For example, MCR users have three printing options. Novice users tend to use either the printer icon in the task bar or to click on the "File" menu and select the "Print" item on the pull-down list. More experienced users know short cuts or combination keys, such as "Ctrl+P" to print. This design methodology accommodates two level of expertise and is consistent with other software applications users are likely to use. Most current cancer registry data management systems today are implemented on Microsoft Windows systems. Identifying alternative displays and flexible features based on user preference helps increase user satisfaction.

Take Home Message

Many data management systems claim to use human-centered design components; however, human-centered principles are mainly applied only at the data representation level. Instead, our team proposes that using HCDID methodology to identify user characteristics and tasks in the system *early* in the design, purchase, and implementation process would better serve and support your cancer registry work.

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