

ADOPTING THE HL7 STANDARD FOR CANCER REGISTRY WORK: CLARIFYING UNRESOLVED ISSUES

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BACKGROUND

Health Level Seven (HL7) is an American National Standards Institute (ANSI) approved standard for electronic data exchange in the health care industry which allows disparate computer systems to talk to each other. It combines codes and variable-length text fields, offering its users great flexibility. Changes in data exchange formats are accommodated easily, allowing timely revisions in the number, length, and positioning of data fields without costly software re-writes. HL7's flexible structure is virtually ideal for cancer registration, where modifications to reporting formats occur frequently. HL7 has the potential to save time, money, and effort for its users.¹ According to the industry, "Since its first version was released in 1987, HL7 has become a widely adopted standard for the exchange of clinical data."²

It is believed that HL7 may become the standard for the exchange of electronic health care information by hospitals, laboratories, radiology and radiotherapy facilities, and other health care organizations in the United States. HL7 is also used in Australia, Canada, England, Finland, Germany, Japan, the Netherlands, and New Zealand. When a critical mass of community-based organizations adopt HL7, governmental agencies may follow suit and require health care data to be reported to them in HL7 format.

The many apparent benefits of HL7 have led the North American Association of Central Cancer Registries (NAACCR) and other standard setters to evaluate its full potential in cancer registration. These interested parties came together in 1998 to explore the technical and practical aspects of HL7 for cancer registration.

The August 1998 Conference

The CDC convened a meeting in August 1998 to begin studying the potential uses of HL7 in cancer registry systems. Representatives from CDC, NAACCR, NCI, SEER, ACOS, NCRA, and other organizations attended. A Summary Report of the meeting was issued in October 1998, outlining the many potential benefits of using HL7 in cancer registry systems.² These included four key benefits:

- Changes in NAACCR's data exchange format would be facilitated,
- Case finding from reporting sources using HL7 would be faster and more convenient,
- Editing queries among registries could be automated, and
- Net gains in human resources could accrue from improved timeliness and efficiency,

and two additional benefits:

- Exchange of data between cancer registries and data users familiar with HL7 would be facilitated, and.
- Software vendors familiar with HL7 might develop useful registry products, increasing competition and lowering the price of registry reporting software.

Conference participants "agreed to develop a draft implementation plan as a first step in exploring a possible NAACCR transition to HL7."² The transition was envisioned not as "an immediate replacement

of NAACCR's existing data exchange format and operations but rather as a parallel reporting system of data that would enable all to evaluate the benefits, hurdles, and practical issues as implementation took place."² Participants agreed to develop a guide for implementing HL7 in cancer registry systems, to be used by software designers. They also mapped out four tasks to be accomplished prior to HL7's adoption:

- Undertake an HL7 consensus-building process,
- Apply for HL7 codes to accommodate cancer registry information,
- Test and disseminate the implementation guide, and
- Work with vendors to stimulate interest in writing new software.

OBJECTIVES

The potential benefits of HL7 technology aside, the practical and policy significance of HL7 operations in central registries needs to be considered. In fact, both the technical and the practical issues need to be addressed at the same time, although not necessarily by the same people. Representatives of NAACCR full members (those working in population-based central cancer registries) were enlisted to identify the practical and policy issues that they foresee in the adoption of HL7. The issues revolved around the use of HL7 as:

- A data exchange standard
- A case finding tool
- An automated method for sending and receiving data queries

METHODS

Ten full members of NAACCR were contacted and interviewed about their perceptions of the unresolved practical and policy issues related to the adoption of HL7 by central registries and by NAACCR. Participants were selected to represent a wide variety of central cancer registries and because their interest in HL7 had been recognized by the NAACCR leadership. Although participants came from the United States only, they represented registries from SEER and NPCR programs, large and small, and from all regions of the country. Some participants had attended the August conference as NAACCR representatives, and some continue to study issues related to the use of HL7 in cancer registry work.

Participants were asked:

- "On the basis of what you know about HL7 and NAACCR's discussion of its potential adoption by central cancer registries, what important issues or problems concerning its use in cancer registration remain unresolved?"

Participants' responses were clarified by asking them:

- "Can you tell me more about that?"
- "Would you explain that for me?"
- "What are the implications of this issue (problem)?"
- "Are there any other implications of this issue (problem)?"

RESULTS

Identifying the Issues

About 75 issues were identified from participants' responses and aggregated into eight key issue-groups, sorted into three major categories:

- Using HL7 as a Data Exchange Standard:
 1. How do we develop new central registry software at reasonable cost?
 2. How do we avoid disruption of ongoing cancer registration?
 3. How do we avoid backlash from reporting institutions?
 4. How do we assure the confidentiality of data?

- Using HL7 as a Case Finding Tool:
 5. How universal will HL7 become?
 6. How can we maximize HL7's potential as a case finding tool?
 7. How accurate is SNOMED coding at present?

- Using HL7 to Automate Editing Queries:
 8. How can we maximize HL7's potential as an editing query tool?

Clarifying the Issues

The meaning of each key issue was clarified by participants during the interviews. These clarifications were collated and edited, to yield the following:

1. How do we develop new central registry software at reasonable cost?

Central registry software is distinctly different from hospital registry software. There are few vendors developing central registry software. HL7 itself is not a central registry software application; it is a data exchange application which can be used to import data to the central registry database and to export data from the central registry database. Questions were raised as to whether existing vendors could accommodate HL7 requirements at a reasonable cost? How generic or specific are the specifications for the interface (called an HL7 reader) between the HL7 software and each registry's unique registry operating software? Expectations that HL7 will enhance competition from new vendors into the central registry software business² may be unrealistic, because the market for central registry software and support services is limited (fewer than 100 potential customers in the United States and Canada). Respondents also wondered whether NAACCR should (in collaboration with government agencies) consider developing standard central registry software at this juncture. They questioned whether a standard interface (HL7 reader) could be developed that would realistically meet the needs of all users for data import and export processes.

2. How do we avoid disruption of ongoing cancer registration?

It has been suggested that the transition to HL7 occur gradually, as a parallel reporting medium. Although many registries work with different cancer data reporting systems and these often represent both manual and electronic systems, HL7 uses a very different format. Central cancer registries

throughout North America do not, at present, have the resources to develop HL7 readers specific to their needs, and some do not have the capability to install, run, or test parallel data collection / editing / transfer systems. The development of an HL7 application that could meet the needs of all users has not been explored, and based on experience with central registry software systems, it seems unlikely that one design will be useful to everyone.

3. How do we avoid backlash from reporting institutions?

HL7's potential to save time, money, and effort for cancer reporting would be maximized if it were used by all reporting sources. The adoption of HL7 throughout the health care industry may be slow, adopted at various rates in different sectors, or it may be incomplete. NAACCR's adoption of HL7 would have to be done in parallel with those segments of the health care industry that are essential to cancer registration. If NAACCR moves too quickly, it might cause significant backlash from reporting institutions that are not ready to adopt HL7. This raises significant concerns about how NAACCR's adoption of HL7 can be coordinated with the changes in the larger health care industry, and if an orderly transition can be planned, devised, and actually implemented.

4. How do we assure the confidentiality of data?

If HL7 is used to its potential in cancer registry systems, the frequency of data transfer will increase dramatically. At one extreme, it is feasible that the flow of information could be continuous: when a facility registrar completes abstracting a record, the file could be immediately transferred to the central registry. While it is likely that at one reporting end or the other, records will need to be batched and held for either reporting or processing, it is still reasonable to expect that the transmissions between facilities and the central registry will increase in frequency.

Although this phenomenon will present challenges to confidentiality, the flexibility of HL7 data transfer may partially ameliorate this problem, by allowing key fields in a case report to be separated, transferred independently of one another, and then reassembled by the recipient of the information. NAACCR and its fellow organizations must continue to work diligently for means by which electronic data transfer may be swift, inexpensive, and secure. The flexibility of HL7 data transfer can be explored to achieve this end.

5. How universal will HL7 become?

If HL7 is not adopted universally in the health care industry, its potential for improving the timeliness and efficiency of cancer registration will not be maximized. Under such circumstances, registrars would have to continue using multiple systems for case identification and case reporting, and keep track of which sources of data require which system. Net gains in human resources projected to accrue from the adoption of HL7 might be neutralized or become a net loss.

Questions were asked during the interviews about the responsibility of NAACCR, beyond preparing its members for HL7, to promote the universal adoption of HL7 in the health care industry. A representative of HL7 has stated that the adoption rate of HL7 will be improved if NAACCR promotes its use among its membership (personal communication, Dr. Clem McDonald, Health Level Seven, Inc., April 9, 1999).

Others felt it was most important for NAACCR to focus on the content of the data elements that NAACCR requires, to ensure that standardization and flexibility will meet our needs, and that we should be less concerned with any particular system that will be the medium for data transfer. This belief grows from the fact that there is no existing universal or universally accepted medium. Whether it is HL7, or

some other format, should be of less importance than whether cancer reporting needs can be met by whatever system becomes the industry standard.

6. How can we maximize HL7's potential as a case finding tool?

The potential for HL7 as a case finding tool will only be realized to the extent that reporting sources:

- Use complete sets of patient identifiers, to avoid ambiguous case identification,
- Use rich narrative information, from which registrars may assign appropriate NAACCR codes, and
- Work to assure the accuracy of coded information.

How and when should NAACCR promote these practices in diverse reporting institutions? At what point in the continuum of HL7 adoption should NAACCR initiate its use as a case finding tool? If we do it too early, we will most likely experience negative reactions from reporting facilities, but if we do it too late, HL7 may not be properly equipped (with specific codes for cancer registration) to meet all cancer reporting standards and requirements.

7. How accurate is SNOMED coding in existing clinical data?

SNOMED codes are used by laboratories to classify diagnostic information for electronic storage and transmission. SNOMED data will be amongst the first to be transmitted to hospital cancer registries and central cancer registries, using HL7 format. SNOMED data, like all coded clinical information, contain inaccuracies. After carefully evaluating the extent of this problem, we can deal with it in two ways. We can disregard SNOMED codes and rely entirely on narrative information, or we can work to improve the accuracy of SNOMED codes in original clinical data. Fortunately, HL7 can handle narrative information as easily as coded information. Thus, both approaches to the use of SNOMED data would be viable, even if future transmission of cancer registry data were to be based on HL7 exclusively.

8. How can we maximize HL7's potential as an editing query tool?

HL7 can facilitate the automation of edit queries among reporting sources and registries. Failed edits, inaccurate codes, or improbable code combinations among several variables could be handled electronically between reporting facilities and the central registry. The entire record could be transferred with editing questions incorporated in the transfer. Information sharing on this scale may be hampered by organizational policies about the confidentiality of the record, access to it, and channels of data transfer. These hurdles will have to be defined and overcome without compromising appropriate organizational objectives for confidentiality and limited access.

CONCLUSIONS

Eight key issues were identified. HL7 has great potential, offering many benefits for cancer registration reporting systems. However, when we weigh the appropriateness of its application to cancer registries, we must go beyond the technical aspects of translation and implementation, considering the practical, administrative, and managerial issues related to its successful implementation, as well. NAACCR needs to study these issues further, with the goal of formulating a strategic plan for the use of HL7 in cancer registry systems.

REFERENCES

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2. Toal S, Lezin N. Working toward implementation of HL7 in NAACCR information technology standards: meeting summary report. Atlanta, GA: Centers for Disease Control and Prevention, 1998. <<http://www.cdc.gov/nccdphp/dpc/npcr/new.htm#exchange>>