Health Information Managers and Clinical Data Repositories: A Natural Fit

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Introduction

Clinical data repositories (CDRs) are becoming the patient records of today and the foreseeable future. It is already clear that all clinical information, regardless of its origin (provider, patient, or even the computer itself), will someday be stored in a data repository (database). Such storage facilitates information access and its use for many different purposes. CDRs are becoming the primary tool for managing patient information, tomorrow's equivalent of the paper chart. In this context, the health information management professional both retains some traditional roles and enjoys new opportunities for professional practice.

So, how can HIM professionals relate to CDRs that their organizations may have or may be contemplating? In general terms, it involves participation in creating the CDR (or helping decide which commercial product to buy), managing its content, and overseeing its use. Let's get more specific about what that means.

Creation

Build or buy? This remains an open question today, although 'buy' is gaining favor. There are an increasing number of CDRs on the market today, but they vary widely in functionality and vendor experience. While a few of the newer systems were designed from the start with a clinical orientation, most are still making the transition from charge capture and billing to support for patient care.

Commercial products tend to be expensive and have ongoing support costs that are significant. On the other hand, CDRs are complex entities, and taking on the task of building one from scratch is a challenging and also potentially costly proposition. Thus, deciding whether an organization's needs can best be met by purchasing a system or by building one is not easy to answer, and it depends a great deal on the nature of the organization and the functionality required. In any event, the HIM professional can play a major part in this process by offering a perspective on several aspects of the data to be contained in the system.

Data Elements

At the root of all data repositories are data elements. The range of data elements includes characteristics of patients (patient name, identification number, address), findings (blood pressure, temperature), results of studies (blood sugar, x-ray), characteristics of a visit or inpatient stay (diagnosis, location of encounter, provider), and more. The HIM professional is trained to be familiar with this universe of data types.

Data Definitions

Each data element also must be defined by associating a name (and other characteristics of the data element) with a meaning. Getting the data definitions correct is vital to the success of any database. For example, "date" has a very simple meaning-or does it? A data element simply named "date" could be the date the computer entry was created, the date the recorded activity took place, a patient's date of birth, the patient's date of death, the date insurance went into effect, etc. So appropriate names and meanings are vital-confusion among data items could be disastrous. In addition to its name, a data element will have a

number of other attributes. An attribute is "a quality or characteristic inherent in or ascribed to someone or something."[1] Some examples follow:

- Specified length-"last name" may be limited to 34 characters
- Formatting rules-"date of birth" may be required in the form MM/DD/YYYY and allow only numbers to be entered
- Integrity checks-"date of death" may be required to follow "date of birth"

Intelligent usage of attributes assists in ensuring valid and accurate data. Data element definitions will form the basis of a data dictionary. Anyone using the data should be able to access the data definitions, preferably online. HIM professionals are trained to be familiar with the attributes of data items.

Data Representation

Data elements will often be stored in some standardized form. For example, diagnoses are most commonly stored as ICD codes. (This begs the question of which form of ICD!) Other standard forms exist, such as SNOMED and READ codes. HIM professionals are trained to be familiar with alternative representations of data and how their potential use may affect the selection of an appropriate representation scheme.

Data Structuring

When defining data elements and constructing the data repository, it's wise to have the assistance of a specialist in data modeling and database design. Data modeling can create a better understanding of data flow-how data is generated, stored, and retrieved. This keeps redundancies and obsolete ideas to a minimum. It can also help determine which data elements to collect. The saying is "Collect everything needed, but nothing more." If you do not collect everything you need, you risk not being able to maximize usage of the data. If you collect unnecessary information, you waste resources by incurring data entry and validation costs, and occupying storage space. Database design describes how data elements relate and how specific arrangements of data make it easier or harder to provide specific functionality, such as display of patient summary information or retrieval of patient groups by diagnosis.

An example of this today might be developing a database (or part of a database) to store information on procedures performed. The first question many HIM professionals would ask is "inpatient or outpatient?" That is because ICD-9-CM is used for inpatient coding and CPT for outpatient. If the answer were both, many might respond, "Well, then you'll need two data elements." That is fine and will satisfy the requirements today, but what about the future? What will happen as clinical vocabularies are developed and new classification systems are added? One solution would be to continue to add new and different data elements. An alternative, cleaner solution would be to still add two data elements, but not one to store ICD-9 and one to store CPT. The first data element might be titled "code type" and contain an indicator that would tell you what system was used for coding (ICD-9-CM, CPT, ICD-10, SNOMED, etc.). The second data element would probably be the actual code. This would enable the system to adapt with minimal effort. The HIM professional is trained to be familiar with issues related to the evolving nature of data elements and the relationships between them.

Oversight

A CDR exists basically for two purposes: to serve as a relatively inert repository documenting patient care and to provide the grist for active processes from clinical decision support to applied epidemiology. While the former is important in a medicolegal sense (and thus drives some of our professional responsibilities), it is the latter that interests most people in the clinical setting. Once a CDR is established, its actual use raises multiple issues. Some are more obvious than others.

Privacy and Confidentiality

Undoubtedly one of the most visible and controversial aspects of clinical data systems is how to achieve a balance between protecting global confidentiality and individual privacy while simultaneously not restricting functionality. This is often a matter of human factors rather than technological ones, but the HIM professional plays an important role in pressing for adequate

system functionality, establishing appropriate organizational policy and procedures, and developing educational materials and providing training.

Proper Use

Users of information systems often lack insight into the data being processed. This can be a matter of understanding a coding scheme. For example, knowing which ICD codes must be searched to retrieve patients with a particular diagnosis where the diagnosis may only be coded as a complication of another. Occasionally, overlooking obvious details contributes to many errors. For example, it is not uncommon for someone constructing a report to forget to ask only for patients who are still alive! As a product of training and experience, the HIM professional has the mix of coding knowledge and data implications necessary to advise users.

Interpretation

Users may not understand the ability of the system to store data or the impact of encoding, such as loss of information. A CDR may contain data from a multitude of sources, and so users may not be familiar with portions of the CDR or with the way that data was acquired. Again, the HIM professional is well positioned to provide users with interpretations critical to correct uses of data in the CDR.

Ironically, if a CDR were not useful and in demand, there would not be any problems. Fortunately, HIM professionals can aid decisions that minimize the impact of these issues.

Management

The basic goal of CDR management is to maximize several aspects of the data being stored: quality, timeliness, comprehensiveness. Comprehensiveness is the scope of coverage of the CDR-the types of data stored. If data coverage is incomplete, conclusions drawn from it may be erroneous, for example, attempting to interpret lab results in the absence of a problem list because the system does not store them. Timeliness is the interval between the occurrence of a clinical event about which data is captured and its appearance in the CDR. If this interval is prolonged, clinicians do not have current data to make decisions, and duplicate data (diagnoses on a problem list drawn from an encounter form) may be generated because data from an earlier encounter has not yet been processed. Quality is an amalgam of both accuracy and precision. Data lacking these attributes may result in failures of decision support systems that depend on data to drive automated reasoning processes, for example, a decision rule relating to diabetic coma that fails because accuracy of data capture is insufficient to indicate coma. The HIM professional plays an important role in helping ensure that ongoing attention is paid to factors that can directly affect these measures. The following represent a small sample.

Data Collection and Validation

Data must be captured in ways that help maximize the attributes just described. Direct data entry by providers at the point of care is the optimum way to achieve timeliness and-with interactive edit checks and give-and-take dialogs-accuracy. However, this optimum approach is not always achievable. As a result, data is frequently entered by surrogates for the original creators. In such circumstances, two opportunities exist for less than perfect data capture: insufficient specificity by the originator and inaccurate replication by a transcriber. Even where no inaccuracy is introduced at these points, there remains the potential for data loss during encoding. HIM professionals can be a powerful influence in motivating accurate and complete data entry by providers. HIM professionals also occupy a crucial position for proposing approaches to data capture, monitoring the data collection process, and supervising data sampling and analysis for quality assurance.

Error Resolution

No matter how good the system, errors will occur. Error correction-and resolution of issues that may underlie their occurrence-is a vital part of the HIM professional's role in operational management of CDRs. As an example, consider a multifacility organization in which one site introduces a new drug into its formulary without following the policy dictating that such additions should be made through a central point so that all systems in the network can be updated. The first time a message containing a reference to that drug is sent to another site, an error will occur because the drug is not in the site's

formulary. The HIM professional is likely to be the best person to track down the source of the error, institute the appropriate corrections, resubmit the message for processing, and deliver education to the staff whose actions caused the error.

Vocabulary Management

Creative tension exists between the need to adequately describe clinical activity and the effort to standardize terminology so that similar entities are represented consistently. Giving in to the temptation to "enhance" a coding scheme (adding terminal digits to ICD codes) could result in a variety of complications, ranging from rejected billings to generation of inaccurate clinical reminders. Thus, the task of vocabulary management-keeping terminology files up-to-date and preventing the adulteration of standard vocabularies-is a key function of health information managers.

Data Retention

Constraints on database size, even with the present, highly favorable economics of disk storage, mean that most sites will not able to keep all data online forever. Thus, establishing consensus on the length of time clinical data will be kept readily available, establishing policies on archiving (or purging, where allowable), and cooperating with information resource management staff to achieve smooth and routine processing in this area are critical operational roles of HIM professionals.

In summary, the health information manager occupies a central position in healthcare facilities with CDRs, and the activities of the health information manager in the ongoing operation of a CDR center on oversight, coordination, and issue resolution.

Complicating Factors

The picture painted so far is complex enough. But things become even more interesting when one considers the impact of current trends in medical economics-managed care, partnerships, mergers-on the functionality demanded of a CDR and consequently on the responsibilities of the HIM professional. Here are three.

Changing Representations

Previously we mentioned the challenge of selecting an appropriate form to represent data. What happens if long after the CDR is operational, perhaps years or even decades later, the ground rules change? This can be something as "simple" as the transition from ICD-9 to ICD-10 or as complex as a shift from ICD-9 to SNOMED. Understanding the impact, managing such conversions, and educating users represent major challenges.

Integrating Multiple Facilities

Getting everything working smoothly in a single facility is tough enough. What happens when the scope is expanded to cover multiple facilities within a single organization? For one thing, information standards become a key concept: which types of data are collected in what settings, coordination of controlled vocabularies for everything from medication names to procedure codes, and agreement on data exchange formats. These are just a few.

Working with External Partners

Everything gets tougher as the scope of operation gets bigger. When the prospect of working with healthcare partners outside of the original organization is introduced, everything is magnified: political and economic considerations, privacy and confidentiality issues, need for data standards, and so on. Collaboration and cooperation are not just concepts; they are essential.

It is these sorts of factors that present the HIM professional with major organizational and intellectual challenges. While they may seem daunting, they are situations with which the well-prepared professional may be uniquely equipped to cope.

Conclusion

The challenges of migrating to CDRs are enormous, but so are the rewards. By moving to CDRs, the healthcare industry one day may be able to move health information as easily as the banking industry moves account information (and money!). Health information managers have the necessary skills to facilitate and manage this transition.

Note

1. Joint Commission on Accreditation of Healthcare Organizations. *Lexikon*. Oakbrook Terrace, IL: Joint Commission on Accreditation of Healthcare Organizations, 1994, p. 126.

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Article citation:
Curtis, Clayton; Fenton, Susan H.. "Health Information Managers and Clinical Data Repositories: A Natural Fit" *Journal of AHIMA* 67, no.4 (April 1996): 48-51.
