Toward Standardization of Health Information

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Although health data standardization has become highly visible in the US during 1996, the National Committee on Vital and Health Statistics (NCVHS) has been working toward greater standardization of health information since its inception nearly 50 years ago. Established in 1949 in response to a recommendation by the World Health Organization (WHO) to all governments, the NCVHS has served continuously as an advisory committee on health information to the secretary of the Department of Health and Human Services (DHHS).

Legislation[3] signed by President Clinton on August 21, 1996, expanded the NCVHS's advisory function in relation to the standardization of specific electronic health data. On that same day NCVHS submitted to the DHHS Data Council its recommendations for standardizing 42 core health data elements, including demographic, socioeconomic, and health status information about a person and data specific to a person's encounter with the healthcare system on either an inpatient or outpatient basis.

NCVHS's report, Core Health Data Elements, was the result of a two-year effort, undertaken at the request of DHHS, to build greater consensus around voluntary standardization of healthcare enrollment and encounter data. While NCVHS considers this an iterative process, building on a nearly 30-year history of uniform data set development and continuing to evolve along with the healthcare system, it believes this report represents a significant watershed. Consensus has been reached on definitions for some of the elements; for others, there is much agreement, but definitions must still be finalized; and for a third group, additional study and testing are needed. This article will highlight some of the key recommendations related to the classification of morbidity data.

Background

In response to pending, and ultimately unsuccessful, national health reform legislation, DHHS charged the NCVHS in 1994 to review the current state of health-related core data sets, obtain input on their collection and use, interact with data standards-setting groups and, most importantly, promote consensus by identifying areas of agreement on core health data elements and definitions. Throughout the process, NCVHS solicited advice from a broad spectrum of public and private-sector collectors and users of encounter and enrollment data, as well as leading organizations actively involved in efforts to standardize health information.

NCVHS's goal has been to develop a set of data elements with agreed-upon standardized definitions that, when needed in a data collection effort, can be used to collect and produce standardized data for multiple purposes. The intent is not to specify a data set for mandated external reporting; the list of recommended data elements is by no means exhaustive and, unlike earlier activities, is not a "data set" to be used in a specific setting. Nonetheless, the recommendations do draw significantly on earlier NCVHS recommendations for the Uniform Hospital Discharge Data Set (UHDDS) and Uniform Ambulatory Care Data Set (UACDS), the vast majority of which were reinforced during the consultation process.

Major Findings

Major findings of NCVHS are as follows:

- The response to NCVHS's activities was solidly in favor of the identification and use of standardized data elements and definitions

- Standardizing a common core of data elements will not only facilitate a comparable level of data quality across organizations, but also should help to reduce both internal and external reporting burdens

- Unless more ways can be found to create greater agreement among suppliers and users of health data in both fee-for-service and managed care environments, innovative efforts such as the development of report cards for use by consumers and purchasers and continuous quality improvement efforts by clinicians and program managers will be thwarted

- There is already consensus among data collectors and users for a significant number of data elements, especially elements related to person descriptors and to selected information on inpatient and ambulatory encounters

- There is less agreement on data definitions, even for data items that have been in the field for years. Definitions must be refined and made available in standardized formats to data collectors

- There are data items, such as health status and functional status, that are considered crucial elements, but for which substantial additional evaluation and testing must be undertaken to reach consensus on standardized content and definition

A complete set of findings and recommendations is contained in the report.

Morbidity Classification

NCVHS's report recommends standardizing a number of elements related to a person's health condition and status and the health services provided to the person. These elements include:

- Self-reported health status
- Functional status
- Principal diagnosis (inpatient)
- Primary diagnosis (inpatient)
- Other diagnoses (inpatient)
- Diagnosis chiefly responsible for services provided (outpatient)
- Other diagnoses (outpatient)
- Patient's stated reason for visit or chief complaint (outpatient)
- External cause of injury
- Principal procedure (inpatient)
- Other procedures (inpatient)
- Procedures and services (outpatient)
- Medications prescribed

Before looking at specific elements, a few summary points should be made. First, as suggested above, currently in the US different guidelines and even different classification systems are required for reporting the same information, depending upon whether the patient received care on an inpatient or outpatient basis. This is a problem, resulting in noncomparable data, that the NCVHS has addressed in a number of past recommendations and that continues to concern the committee. This situation may be alleviated for diagnosis reporting with the implementation of a clinical modification of the 10th revision of the International Classification of Diseases (ICD-10).

A second issue relates to the source of the information reported; NCVHS believes that in some cases information reported by the patient can be equally as important as clinician-reported information, and it has made recommendations for collecting both. However, this may require the use, and attendant burden, of multiple classification systems unless there is more convergence among systems. NCVHS has been following the development by the National Library of Medicine (NLM) of the Unified Medical Language System (UMLS) Metathesaurus; the NLM currently is sponsoring a large-scale vocabulary test to determine the extent to which a combination of existing health-related classifications and vocabularies cover vocabulary needed in information systems supporting healthcare.

Third, and related to the second, for several of these elements the NCVHS found no agreed-upon definition or classification system, thus requiring additional work and evaluation. It chose to include these elements in its recommendations because of the growing consensus that they increasingly will be used to understand healthcare needs and outcomes. Also, NCVHS wants to encourage the DHHS and its partners to give high priority to conducting evaluation and research on such elements and seeks to alert organizations developing standards or data sets to leave "place holders" for their future inclusion.

Fourth, the ongoing maintenance and updating of a classification system has been recognized in the past by NCVHS as a significant issue and has gained prominence in the recently enacted legislation cited earlier in this paper. That legislation requires appropriate consultation in the modification of all standards and requires that the secretary of DHHS "establish efficient and low-cost procedures for distribution...of code sets and modifications made to such code sets" and "ensure that procedures exist for the routine maintenance, testing, enhancement, and expansion of code sets." Although the legislation states that the secretary shall adopt modifications to standards "as determined appropriate, but not more frequently than once every 12 months," an exception is made "with respect to additions and modifications to code sets…."

Some specific morbidity classification issues addressed in the report follow. The full discussion of each element noted above can be found in the committee's report.

Self-reported Health Status

NCVHS found considerable interest in documenting self-reported health status as an element that can precipitate the demand for healthcare and help determine prognosis. However, there was no consensus on how its definition should be standardized. While recognizing the need for further study, NCVHS for the first time has recommended collecting at initial clinical visit and periodically thereafter the person's rating of his or her own general health, as in the five-category classification: excellent, very good, good, fair, or poor. When collected in a general interview type of setting, this measure, commonly used in the National Health Interview Survey and many other studies, has been shown to be predictive of morbidity, mortality, and future healthcare use. How this might differ in a clinical setting requires additional study.

Functional Status

NCVHS devoted considerable attention to standardizing the collection of functional status as an element that has been shown to be strongly related to medical care utilization rates and the need for long term care. Again, a number of scales or classification systems, including the International Classification of Impairments, Disabilities and Handicaps (ICIDH) were considered, but there was no consensus on which should be adopted. Furthermore, they all involved the burden of an additional classification system or instrument that is not widely used in healthcare reporting, at least in acute care settings. Of particular importance was the recognition by NCVHS that understanding functional status may require use of several elements and systems, because self-reported and clinician measurements are each valuable and, wherever possible, both should be available. Another complexity relates to the needs and demographics of the specific patient population. At present, for example, there is no widely recognized instrument for measuring the functional status of children, an issue that is being addressed in the ICIDH revision process.

Diagnoses: Guidelines for Reporting

In the US, the clinical modification of the International Classification of Diseases, ninth revision (ICD-9-CM), is the required classification system for reporting diagnoses in both inpatient and outpatient settings. However, different coding guidelines currently apply to these two settings.

The official inpatient guidelines state, "If the diagnosis documented at the time of discharge is qualified as 'probable,' 'suspected,' 'likely,' 'questionable,' 'possible,' or 'still to be ruled out,' code the condition as if it existed or was established. The basis for this guideline are the diagnostic workup, arrangements for further workup or observation, and initial therapeutic approach that correspond most closely with the established diagnosis."[4] Alternatively, the official national outpatient/physician coding and reporting guidelines provide instruction that a suspected or rule out condition not be reported as though it is a confirmed diagnosis. The instruction clarifies that only what is known to the highest level of specificity should be reported. In some instances this may be a symptom or an abnormal finding.

The NCVHS has stated in earlier recommendations on the UHDDS (1992) that it is problematic to have different guidelines for coding diagnoses in inpatient and outpatient settings, and that the outpatient guidelines result in more accurate data and should apply in both settings. At the same time, it has recognized that the responsibility for specifying the certainty of a diagnosis belongs to the attending physician and should not be borne by the coder. The WHO Collaborating Center for the Classification of Diseases for North America, located at NCHS, is responsible for the coordination of all official disease classification activities in the US relating to the ICD and its use, interpretation, and periodic revision. NCHS has stated its interest in moving toward convergence of the inpatient and outpatient guidelines with the introduction of the clinical modification of ICD-10.

In developing the Core Health Data Elements report, a further issue arose. While Medicare and many other payers adhere to the two sets of guidelines, some third-party payers have ignored the outpatient guidelines and require facilities and physicians always to report a diagnosis that justifies the performance of services being provided even when the diagnosis has not been established. This has resulted in inconsistent data in ambulatory databases and has skewed studies of resource utilization and patient outcomes. For example, a patient who eventually is established to have diabetes will have quite different needs and prognosis than one whose symptoms are found to be related to a more limited, acute condition.

Persons providing testimony at the two special NCVHS meetings convened on core health data elements were asked to comment on whether their data systems were able to identify the certainty of diagnosis in either inpatient or outpatient settings or whether these systems could be modified to include this information. In its second mailing to the field, the NCVHS suggested adding an additional element to the diagnoses collected in the outpatient setting, "physician's tentative diagnosis." This diagnosis would have contained "the code(s) for the condition(s) or problem(s) that explain the clinician's assessment of the presenting symptoms/problems and corresponds to the tests or services provided." The ICD-9-CM continued to be the recommended coding convention. Feedback from the field suggested that collection of a tentative diagnosis, even if maintained separately, would be confusing and could result in inappropriately labeling patients with unconfirmed diagnoses, the very problem that the proposal was attempting to address. Thus, the report eliminated this proposed element; the report does note the interest by some in collecting provider certainty of diagnosis and recommends continued monitoring of provider practices with regard to coding and compliance with coding guidelines.

Principal and Primary Diagnosis (inpatient)

As recommended by the UHDDS, the principal diagnosis is defined as "the condition established after study to be chiefly responsible for occasioning the admission of the patient to the hospital or nursing home for care." The committee recognizes that principal diagnosis is required by most systems for inpatient reporting and thus considers it to be a critical core data element. At the same time, during this and earlier reviews, it noted some interest in collecting the "primary diagnosis" and also some confusion between the terminology of principal versus primary. For this reason, the NCVHS's report defines primary diagnosis as "the diagnosis that is responsible for the majority of the care given to the patient or resources used in the care of the patient." The report observes that in most diagnostic situations, the principal and primary diagnoses will be identical.

Other Diagnoses and Qualifier for Other Diagnoses (inpatient)

Again, as recommended by the UHDDS, "Other Diagnoses" are defined in the inpatient setting as "all conditions that coexist at the time of admission, or develop subsequently, which affect the treatment received and/or the length of stay." Diagnoses that refer to an earlier episode that have no bearing on the current hospital or nursing home stay are to be excluded. In addition, the NCVHS recommends that a qualifier should be applied to each diagnosis coded under "other diagnoses" as to whether the onset was prior to admission or not prior to admission. This qualifier was recommended in the 1992 revision of the UHDDS, which noted that the element was currently being collected by California and New York hospital discharge data systems. These systems report that use of this qualifier can contribute significantly to quality assurance monitoring, risk-adjusted outcome studies, and reimbursement strategies.

Problem, Diagnosis, or Assessment (outpatient)

NCVHS has divided this element, which describes all conditions requiring evaluation and/or treatment or management at the time of the encounter, as designated by the healthcare practitioner, into two separate elements: (1) the diagnosis chiefly responsible for services provided and (2) other diagnoses. The former is defined as "the diagnosis, condition, problem, or the

reason for encounter/visit chiefly responsible for the services provided"; the latter are the additional code(s) that describes any coexisting conditions (chronic conditions or all documented conditions that coexist at the time of the encounter/visit, and require or affect patient management).

Patient's Stated Reason for Visit or Chief Complaint (outpatient)

In its 1994 recommendations on the UACDS, the NCVHS recommended that high priority should be given to conducting additional study as to the feasibility, ease, and practical utility of collecting the patient's reason for seeking attention or care at the time of the ambulatory encounter, in as close to the patient's words as possible. The Core Health Data Elements report reinforces the importance of knowing what motivated the patient to seek care; such information is useful, and perhaps critical, for analyzing the demand for healthcare services, evaluating quality of care, and performing risk adjustment. Currently, this element is not collected routinely, and there is no one agreed-upon coding system for this item, although the International Classification of Primary Care (ICPC) is one system that warrants additional evaluation and testing. Compatibility between the ICPC and ICD will be of particular importance. It should be noted that for 20 years NCVHS has used a variation of the ICPC, the Reason for Visit Classification, to code and classify the patient's stated reason for visit or chief complaint in national ambulatory care surveys.

External Cause of Injury

Since 1991, the NCVHS has been a strong advocate for the collection of external cause-of-injury codes (E codes) whenever there is a diagnosis of an injury, poisoning, or adverse effect. NCVHS recognizes that the information that this element provides on the causes of patients' injuries or adverse effects is essential for the development of intervention, prevention, and control strategies. NCVHS's first recommendations for E coding related to inpatient reporting and were influential in E code collection on the uniform bill for hospitals in the US. Currently, 17 states mandate collection of E codes in their hospital discharge data systems, although no payer currently requires them. The NCVHS also identified a number of deficiencies in the E code classification system, which were addressed in an NCHS evaluation study.

In 1994, the NCVHS further recommended that a separate element for an E code be added to the uniform bill for physician and outpatient reporting, although this has not occurred to date. NCVHS has responded on several occasions to objections raised about reporting E codes, particularly for chronic exposures, and continues in its report to recommend their collection. It is hoped that the inclusion of external causes as a chapter in ICD-10, rather than a supplemental classification, will further acceptance of their use.

Procedures

Unlike diagnosis reporting in the US, two different classification systems are required for reporting medical and related services and procedures. Volume 3 of ICD-9-CM was developed to classify procedures performed during inpatient hospital stays; the Physician's Current Procedural Terminology (CPT) was developed and is maintained by the American Medical Association (AMA) to classify procedures performed by physicians in both inpatient and outpatient settings. Payment and other considerations require both classifications to be coded when the patient is hospitalized. The two classifications have widely differing conceptual foundations, maintenance and updating systems, advantages, and limitations. The two systems are sufficiently different that they cannot be "crosswalked" on a code-to-code basis.

After considerable study, during which NCVHS sought advice from a wide range of organizations and individuals who have a stake in procedure classification, the NCVHS submitted a report to DHHS in 1993 recommending development and adoption of a single system for classification of healthcare services and procedures to be used in all settings in which healthcare is delivered in the US. This recommendation was made with the recognition that adequate resources would be needed to support all aspects of development, implementation, evaluation, education, and maintenance.

NCVHS continues to strongly advocate a single procedure classification system for inpatient and outpatient care and in 1994 developed an outline of the criteria for a unified procedure classification system. However, its recommendations for standardizing core health data elements reflect the current practice and requirement of using ICD-9-CM, Volume 3, for inpatient reporting and CPT-4 for physician, hospital outpatient department, and freestanding ambulatory surgical facility reporting. NCVHS is following with great interest the development by the Health Care Financing Administra-tion of a

procedure classification system to replace Volume 3 for inpatient reporting and the creation by the AMA of the CPT Exploratory Committee to evaluate CPT for long-term needs of health professionals.

It should be noted that the NCVHS's report recognizes the need to collect information on relevant services provided by all healthcare practitioners, not just those provided by physicians. This also is one of the issues being examined by the AMA committee.

Medications

NCVHS recommended, in its 1989 report on the UACDS, collecting information on whether medications were prescribed during an ambulatory encounter. Since that time considerable progress has been made in standardizing information on drugs; further, performance measurement activities increasingly address appropriate use of medications. Core Health Data Elements recommends the element, "Medications Prescribed," which is defined as "all medications prescribed or provided by the healthcare practitioner at the encounter (for outpatients) or given on discharge to the patient (for inpatients), including, where possible, National Drug Code, dosage, strength, and total amount prescribed."

Summary

NCVHS has made recommendations to the DHHS to standardize 42 core health data elements, a number of which relate to medical conditions and services. The committee has asked the DHHS Data Council to actively promote, both within the department and externally, standardization of data elements and definitions where substantial consensus already exists. For those elements that have been recognized as significant core data elements, but for which there is not consensus on approach or definition, the NCVHS is recommending that the Data Council support the formation of a public-private working group to conduct further study and evaluation. This group, or a separate group, could also be the focus for evaluating additions to the list of core data elements and for setting up methods for testing and promulgating the final products. The coming 12-18 months will be exceedingly important for health data standardization efforts in the US as the DHHS responds to both the NCVHS recommendations and the legislation recently enacted by Congress.

Note: An earlier version of this paper was presented at the Annual Meeting of Heads of WHO Collaborating Centres for the Classification of Diseases, which was held in Tokyo, Japan, October 15-21, 1996. Copies of the NCVHS report Core Health Data Elements can be obtained from the National Center for Health Statistics, 6525 Belcrest Rd., Room 1100, Hyattsville, MD 20782, attention: Jacqueline Adler. The report also can be accessed from the NCVHS home page at http://aspe.os.dhhs.gov/ncvhs/.

Notes

1. The National Center for Health Statistics (NCHS) serves as executive secretary to the National Committee on Vital and Health Statistics, consistent with the NCHS director's role as senior advisor for health statistics to the secretary of the Department of Health and Human Services (DHHS).

2. Judith Miller Jones retired as chair of the National Committee on Vital and Health Statistics on September 18, 1996, after serving eight years as a member of the committee, the last five as its chair.

3. The Health Insurance Portability and Accountability Act of 1996 (PL 104-191) makes several important changes in health insurance coverage and also requires DHHS to develop content, transmission, and security standards for data related to electronic claims or equivalent encounter data under "Administrative Simplification" provisions. The legislation includes language that DHHS "shall rely on the recommendations of the National Committee on Vital and Health Statistics (NCVHS)," as well as consulting with others, on implementing these provisions. The statute further charges DHHS to make detailed recommendations to Congress on standards with respect to the privacy of individually identifiable health information and again names the NCVHS as advisory on these issues. Finally, the NCVHS is required to develop recommendations to the secretary of DHHS and Congress on "uniform data standards for patient medical record information and the electronic exchange of such information" not later than four years after the date of enactment.

4. Developed by AHA, AHIMA, HCFA, NCHS. *ICD-9-CM Official Guidelines for Coding and Reporting.* Chicago: AHIMA, 1994, p. 6.

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