
Capturing and Classifying Functional Status Information in Administrative Databases

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The health care delivery system aims to improve the functioning of Americans, but little information exists to judge progress toward meeting this goal. Administrative data generated through running and overseeing health care delivery offer considerable information about diagnoses and procedures in coded formats comparable across settings of care. This article explores the issues raised when considering adding coded information about functional status to administrative databases throughout the health care system. The National Committee on Vital and Health Statistics (NCVHS) identified the International Classification of Functioning, Disability and Health (ICF) as the only viable code set for consistently reporting functional status.

INTRODUCTION

National health expenditures in the United States topped \$1.5 trillion in 2002, with outlays expected to exceed \$2.8 trillion (17 percent of the gross domestic product) by 2011 (Heffler et al., 2002). Governmental programs pay nearly one-half of these costs, but individuals also spent roughly \$227 billion out-of-pocket in 2002. Questioning what we are buying for these health care dollars, for populations and individuals, therefore seems reasonable.

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The President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry (1998) stated that: "The purpose of the health care system must be to continuously reduce the impact and burden of illness, injury, and disability and to improve the health and functioning of the people of the United States." Is the health care system meeting these goals?

Answering this question requires data. Federal and local surveys, special studies, and anecdotes strongly suggest that our health care system often fails to achieve these goals (Institute of Medicine 1999, 2001a, 2002a, b, c; U.S. Department of Health and Human Services, 2000; World Health Organization, 2000; McGinnis, Russo, and Knickman, 2002; Berwick, 2002). However, most of these judgments rely on examining mortality rates, complications of care, or use of specific services. Little systematic information is available about the health care system's performance across delivery settings and patient populations for improving the health and functioning of Americans.

Administrative data—information generated through overseeing public and private health insurance, enrolling health plan members, paying bills, and other administrative activities—offer systemwide information about health conditions and services in a consistently coded format.¹ Providers' claims, bills, and encounter records report diagnoses using *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-

¹ By definition, administrative data generally exclude uninsured persons, estimated at 15 percent of the population in 1999 (Institute of Medicine, 2001b).

CM) (Centers for Disease Control and Prevention, 2003) codes, despite reservations about their accuracy, completeness, clinical scope, and meaningfulness (Hsia et al., 1988, 1992; Iezzoni, 1997a, b, 2002; Lawthers et al., 2000; McCarthy et al., 2000; Romano, Schembri, and Rainwater, 2002). Thus, the nature and scope of illnesses and injuries are known when people seek and obtain covered care. Providers report services using: ICD-9-CM procedure codes for claims submitted by institutions, such as hospitals; the *Current Procedural Terminology*[®] (CPT[®]) (American Medical Association, 2003) for individual physician services; or the Healthcare Common Procedure Coding System (2003a) for non-physician services not in CPT, including durable medical equipment. When prescription drugs are covered, pharmacy claims identify pharmaceuticals, generally using National Drug Codes (U.S. Food and Drug Administration, 2003).

Coded administrative data thus can provide insights into the health care system, especially concerning disease burden, clinical interventions, and selected outcomes (primarily expenditures and mortality) for insured populations (Clancy and Eisenberg, 1997). For instance, longitudinal analyses of Medicare claims showed that, between 1987 and 1995 among males age 75 to 79, procedure rates grew by 20 percent for angioplasty, 18 percent for hip replacements, and 12 percent for knee replacements (Fuchs, 1999). Greater use of such services caused much of the recent growth of Medicare expenditures. However, these figures revealed nothing about the functional status of these males or whether surgery improved their ability to conduct daily activities—whether these interventions fulfilled proposed goals of our health care system.

A gap therefore exists between national health care system goals and the data routinely available to measure performance,

as well as to manage resources to improve efficiency and quality of care. This concern led the NCVHS, the advisory committee on health information policy to the U.S. Department of Health and Human Services, to conclude:

“Achieving optimal health and well-being for Americans requires an understanding across the life span of the effects of people’s health conditions on their ability to do basic activities and participate in life situations—in other words, their functional status.” (National Committee on Vital and Health Statistics, 2001.)

This article examines issues that would be raised by routinely collecting comparable information on functional status on administrative records throughout the health care delivery system.² We focus specifically on generating functional status information (FSI) that is comparable across health care settings, just as ICD-9-CM diagnosis codes presumably offer consistent diagnostic information regardless of data source. As the NCVHS observed, having similar functional information across care settings will maximize the utility of the information for such purposes as evaluating health care system performance and setting funding priorities. However, producing comparable functional information across care settings will require a classification approach similar to ICD-9-CM for diagnoses.

Although FSI is currently gathered throughout the health care delivery system, its content and formats vary widely. Therefore, we begin by describing current mandates for collecting FSI, which specifically involve post-acute and long-term care (LTC). Next we address how functional status is measured and documented elsewhere throughout the health care system. We

² As did the NCVHS, here we concentrate on functioning rather than health, presuming that functioning is an observable characteristic that can be assessed by others, whereas health involves personal perspectives, preferences, and expectations.

argue that making sense of these divergent data requires a consistent classification approach; the NCVHS (2001) identified the World Health Organization's (2001) ICF as the only viable code set for classifying functional status in clinical and administrative records. We address the logistical hurdles to implementing ICF codes in administrative data sets and conclude by suggesting potential uses of coded FSI. We presume that routinely capturing FSI throughout the entire health care system would require:

- Measurement of functional status during clinical encounters.
- Documentation of this assessment in medical records or some other site.
- Coding of FSI in a consistent fashion across settings of care using a comprehensive classification system.
- Capturing this coded information in routine, electronic administrative transactions.
- Using this information for specific and valuable purposes.

CURRENT MANDATES FOR FSI

FSI is already routinely gathered for administrative purposes, specifically to pay and oversee post-acute and LTC. Medicare requires that these providers submit FSI using: the minimum data set (MDS), administered quarterly in nursing homes and containing more than 400 items (Morris, Murphy, and Nonemaker, 1995; Hawes et al., 1997); the Outcome and Assessment Information Set (OASIS), collected during home health care visits, including roughly 80 items (Shaughnessy, Schlenker, and Hittle, 1995; Shaughnessy et al., 1997, 2002); and the Patient Assessment Instrument (PAI) for Inpatient Rehabilitation Facilities (IRF), including more than 50 items (IRF-PAI) (Centers for Medicare & Medicaid Services, 2002a, 2003b).

Under mandates of the Balanced Budget Act of 1997, these post-acute and LTC providers now receive prospective payments based on algorithms derived from these data systems (Medicare Payment Advisory Commission, 2002). Since 1998, Medicare has paid skilled nursing facilities based on 44 resource utilization groups derived from MDS data. Starting in 2001, Medicare has based home health agency payments on 80 home health resource groups produced from OASIS data. Since 2002, Medicare has used 385 case-mix groups generated from the IRF-PAI to pay inpatient rehabilitation facilities. Although these functional status data explicitly support payment, CMS plans to use them in the future also to report on provider performance. The first such effort involved CMS's fall 2002 release of nursing home performance measures based heavily on the MDS (Centers for Medicare & Medicaid Services, 2003d; U.S. General Accounting Office, 2002).

The MDS, OASIS, and IRF-PAI contain dozens of functional status items and thus offer rich insight into patients' functioning in these care settings. However, the three instruments rely on different data items to elicit this information. Thus, the information is not comparable across care settings for post-acute and LTC populations despite their generally similar clinical concerns. This problem prompted the Medicare Payment Advisory Commission (2001) to recommend development of a single "...patient classification system that predicts costs within and across post-acute settings...." The Medicare, Medicaid, and State Children's Health Insurance Program Benefits Improvement and Protection Act of 2000 requires the Secretary of Health and Human Services to submit to Congress by 2005: "...a report on the development of standard instruments for the assessment of the health

Table 1
New York Heart Association Functional Class and Applicable ICF Codes

Clinical Definition of Functional Class	ICF Codes
I Patients with cardiac disease but without resulting limitations of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea, or anginal pain.	b4552.0 fatiguability, no problem b455.0 exercise tolerance functions, no problem b460.0 sensations associated with cardiovascular and respiratory functions, no problem b28011.0 pain in chest, no problem
II Patients with cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea, or anginal pain.	b4552.1 fatiguability, mild problem b455.1 exercise tolerance functions, mild problem b460.1 sensations associated with cardiovascular and respiratory functions, mild problem b28011.1 pain in chest, mild problem
III Patients with cardiac disease resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary physical activity causes fatigue, palpitation, dyspnea, or anginal pain.	b4552.2 fatiguability, moderate problem b455.2 exercise tolerance functions, moderate problem b460.2 sensations associated with cardiovascular and respiratory functions, moderate problem b28011.2 pain in chest, moderate problem
IV Patient with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of cardiac insufficiency or of the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.	b4552.3 fatiguability, severe problem b455.3 exercise tolerance functions, severe problem b460.3 sensations associated with cardiovascular and respiratory functions, severe problem b28011.3 pain in chest, severe problem

NOTES: The letter b in the first position indicates the body functions section from the *International Classification of Functioning, Disability and Health* (ICF) codes. Modifiers after the decimal place indicate the extent or magnitude of the impairment on a generic, negative scale. The modifiers have the following meanings: 0—no impairment (e.g., none, absent, negligible, 0-4 percent); 1—mild (e.g., slight, low, 5-24 percent); 2—moderate (e.g., medium, fair, 25-49 percent); 3—severe (e.g., high, extreme, 50-95 percent); and 4—complete (e.g., total, 96-100 percent). Applicable *International Classification of Diseases, Ninth Revision, Clinical Modification*, diagnosis codes include: for cardiac disease: 413.9—other and unspecified angina pectoris, 414.9—chronic ischemic heart disease, unspecified, 428.0—congestive heart failure, 780.7—malaise and fatigue, 785.1—palpitations, 786.0—dyspnea and respiratory abnormalities; and for anginal pain: 411.1—intermediate coronary syndrome, 413.9—other and unspecified angina pectoris, 786.50—chest pain, and unspecified; 786.51—precordial pain.

SOURCES: (World Health Organization, 2001; Centers for Disease Control and Prevention, 2003.)

and functional status of patients” for whom a wide array of Medicare services are provided. This mandate might “...provide the opportunity for dialogue about what measures to collect, how to collect them, and in what format...” (Bierman, 2001).

Assessing Functional Status in Other Settings

Despite their differences, the MDS, OASIS, and IRF-PAI impose a standard format on assessing and documenting functional status within their respective care settings. In general acute care hospitals and outpatient clinics and offices, however, clinicians use countless different methods for assessing functional status; documentation is often sporadic. Many clinicians routinely assess functional status informally, such as by observing patients getting into

offices or onto examining tables. Some assessments rely largely on asking patients how their health conditions affect daily activities rather than on rigorous physical examinations. For example, the New York Heart Association functional assessment for cardiovascular disease (Table 1) reflects how cardiac symptoms impede patients’ usual activities. Similarly, the Karnofsky Performance Status measure (Karnofsky et al. 1948), a 100-point scale originally developed for cancer patients, indicates patients’ ability to perform daily tasks (Table 2).

Hundreds of disease-specific functional status measures exist for clinical applications, especially for older persons and individuals with chronic conditions (McDowell and Newell, 1987; Kane and Kane, 2000; Mapi Research Institute, 2002). For assessing functional status in multiple sclerosis (MS), for instance, clinicians typically

Table 2
Karnofsky Performance Status and Applicable ICF Codes¹

Clinical Definition	ICF Codes
0-40 Percent: Unable to care for self. Requires equivalent of institutional or hospital care. Disease may be progressing rapidly.	d599.3 self-care, unspecified, severe problem
40-70 Percent: Unable to work. Able to live at home, care for most personal needs. A varying amount of assistance is needed.	d599.2 self-care, unspecified, moderate problem d859.4 work and employment, other specified and unspecified, complete problem
70-100 Percent: Able to carry on normal activity and to work. No special care is needed.	d599.1 self-care, unspecified, mild problem d859.1 work and employment, other specified and unspecified, mild problem d230.1 carrying out daily routine, mild problem

¹ Applicable *International Classification of Functioning, Disability and Health (ICF)*, *International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM)* codes would record the underlying medical condition.

NOTES: The codes assigned to the Karnofsky Performance Status measure have the letter d in their first position, indicating that they are from the activities and participation section of ICF. Modifiers after the decimal place indicate the extent or magnitude of the impairment on a generic, negative scale. The modifiers have the following meanings: 0—no impairment (e.g., none, absent, negligible, 0-4 percent); 1—mild (e.g., slight, low, 5-24 percent); 2—moderate (e.g., medium, fair, 25-49 percent); 3—severe (e.g., high, extreme, 50-95 percent); and 4—complete (e.g., total, 96-100 percent).

SOURCES: (Karnofsky et al., 1948; World Health Organization, 2001; Centers for Disease Control and Prevention, 2003.)

use the Expanded Disability Status Scale (EDSS) (Kurtzke, 1983), but at least eight other MS-specific options exist, including the Multiple Sclerosis Functional Composite and the Cambridge Multiple Sclerosis Basic Score (Institute of Medicine, 2001c). The scales often require discussions with patients about their daily lives as well as more formal functional assessments by clinicians, as suggested by examples of several levels from the 0-10 point EDSS (Table 3). Describing the full range of clinical functional status assessment methodologies is beyond our scope here.

After hearing from diverse experts on assessing functional status, the NCVHS (2001) concluded that "...the science of functional status measurement is still under development and that no consensus yet exists on how to define and measure this complex phenomenon." Nonetheless, several observations are pertinent. First, although many clinicians do assess functioning even through informal means, others do not. Some primary care physicians have little appreciation for their patients' functional abilities and the impact of health conditions on daily lives (Nelson et al., 1983; Calkins et al., 1991, 1994; Cassel, 1997). In studies where physicians were

actively informed of patients' health status, most (approximately 80 percent) considered this feedback useful, but less than one-half changed patient management based on the information (Espallargues, Valderas, and Alonso, 2000).

Second, various clinical disciplines analyze functioning using different nomenclatures, tools, metrics, and perspectives; nevertheless, the basic concepts and constructs which comprise human functioning are universal. The functional status of all persons can be assessed within similar and broadly defined areas, such as physical, sensory, cognitive, and psychological dimensions. Third, although detailed protocols exist to assess developmental milestones, fewer functional status measures exist for children than for adults. Assessing functioning in children is complicated by the inability, especially of small children, to answer questions themselves. More work is needed to develop comprehensive measures of functioning across different dimensions for children of all ages.

Finally, even if clinicians assess functional status, documentation is often sporadic (Bierman, 2001). Bogardus and colleagues (2001) examined records for 525 persons age 70 or over admitted for medical diag-

Table 3
Selected Levels from the 0-10 Point Expanded Disability Status Scale for Multiple Sclerosis¹ and Applicable ICF Codes

Clinical Definition	ICF Codes
4.0 Fully ambulatory without aid, self-sufficient, up and about some 12 hours a day despite relatively severe disability. Able to walk without aid or rest some 500 meters.	d4500.0 walking short distances, no problem
4.5 Fully ambulatory without aid, up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance, characterized by relatively severe disability. Able to walk, without aid or rest for some 300 meters.	d4500.1 walking short distances, mild problem d8502.1 full-time remunerative employment, mild problem
5.0 Ambulatory without aid or rest for about 200 meters; disability severe enough to preclude full daily activities (e.g., to work full day without special provisions).	d4500.2 walking short distances, moderate problem d8502.3 full-time remunerative employment, severe problem
5.5 Ambulatory without aid or rest for about 100 meters; disability severe enough to preclude full daily activities.	d4500.3 walking short distances, severe problem d230.3 carrying out daily routine, severe problem
6.0 Intermittent or unilateral constant assistance (cane, crutch, or brace) required to walk about 100 meters with or without resting.	d4500.3 walking short distances, severe problem e1201.+2 assistive products and technology for personal indoor and outdoor mobility and transportation, moderate facilitator
6.5 Constant bilateral assistance (canes, crutch, or braces) required to walk about 20 meters without resting.	d4500.4 walking short distances, complete problem e1201.+1 assistive products and technology for personal indoor and outdoor mobility and transportation, mild facilitator
7.0 Unable to walk beyond about 5 meters even with aid. Essentially restricted to a wheelchair. Wheels self in standard wheelchair and transfers alone. Active in wheelchair about 12 hours a day.	d4500.4 walking short distances, complete problem d465.0 moving around using equipment, no problem d4200.0 transferring oneself while sitting, no problem e1201.+4 assistive products and technology for personal indoor and outdoor mobility and transportation, complete facilitator
7.5 Unable to take more than a few steps. Restricted to wheelchair. May need aid to transfer. Wheels self but cannot carry on in standard wheelchair for a full day. May require a motorized wheelchair.	d465.2 moving around using equipment, moderate problem d4200.1 transferring oneself while sitting, mild problem

¹ Applicable *International Classification of Functioning, Disability and Health* (ICF) and *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) codes would record the underlying medical condition. ICD-9-CM Code 340—multiple sclerosis.

NOTES: These ICF codes start with the letters d or e, indicating the environmental factors section of the ICF. For e codes, modifiers after the decimal place without a + sign indicate barriers. Those with + signs have the following meanings: +0—no facilitator (e.g., none, absent, negligible, 0-4 percent); +1—mild facilitator (e.g., slight, low, 5-24 percent); +2—moderate facilitator (e.g., medium, fair, 25-49 percent); +3—substantial facilitator (e.g., high, extreme, 50-95 percent); and +4 = complete facilitator (e.g., total, 96-100 percent).

SOURCES: (Kurtzke, 1983; World Health Organization, 2001; Centers for Disease Control and Prevention, 2003.)

noses to an academic medical center; they compared activities of daily living (ADL) and instrumental ADL (IADL) information gathered by interviewing patients with information documented in their medical records. With the exception of walking, individual ADL and IADL items were missing from 61 to 98 percent of records; data on walking were missing in 24 percent of charts. The discordance between functional problems reported by patients and medical record documentation was high. Therefore, "...assuming the lack of docu-

mentation of a particular variable ... implies that that variable is 'normal' may not be valid." (Bogardus et al., 2001.)

Coding FSI

In considering adding FSI to administrative records, the NCVHS drew a clear distinction between measuring or assessing functional status and coding or classifying the results of this measurement. To use an acute disease analogy, clinicians employ many diagnostic methods to evaluate

whether patients have pneumonia, including: examining signs and symptoms, like fever and cough; auscultating or percussing the chest; scanning chest radiographs for infiltrates; and checking sputum for bacteria. At the end of this process, clinicians determine whether patients have the clinical entity pneumonia, which is classified or represented by a particular ICD-9-CM diagnosis code. When the pneumonia ICD-9-CM code appears on administrative records from any health care setting, presumably those patients have the same clinical condition, pneumonia, regardless of how they were diagnosed. Coding rules for administrative records (e.g., for assigning principal and secondary diagnosis codes on hospital discharge abstracts) do not specify how diseases like pneumonia should be measured or diagnosed.

In discussing the reporting of FSI in administrative records, the NCVHS adopted a similar perspective: administrative records should contain codes representing functional status concepts without specifying exactly how functional status is measured. In other words, clinicians could use whichever functional assessment method best suits the diagnostic and therapeutic context, such as the Karnofsky scale (Table 2) for cancer patients and EDSS (Table 3) for MS patients. Then, the key issue becomes coding FSI using a consistent coding scheme analogous to ICD-9-CM, so that the information can be compared and combined across populations and settings of care. Since core dimensions of basic human functioning are virtually universal, a single coding classification scheme could capture these common concepts. The NCVHS (2001) determined that the ICF is currently the only reasonable option for classifying functional status in clinical and administrative records.

Thus, according to the NCVHS (2001), “A coding system that specifies the elements of functioning is an appropriate place to start dealing with the measurement and interpretation of functional status.” The NCVHS based this conclusion, in part, on the “...expectation that a uniform coding instrument could mitigate some of the challenges related to functional status measurement, especially those related to the multiplicity of tools and definitions.” A uniform code set would allow health care providers to “...consistently report on their findings across the continuum of care, for clinical and administrative purposes.” The NCVHS felt that the ICF provides the necessary common language for consistent classification of FSI.

Üstün and colleagues (2003) describe ICF and its history in detail. Briefly, the ICF organizes its codes into 30 chapters grouped under four broad headings: (1) body functions (physiological functions, including cognitive and psychological functions); (2) body structures (anatomical parts of the body, such as organs, limbs, and their components); (3) activities (execution of tasks or actions by individuals) and participation (involvement in life situations); and (4) environmental factors (the physical, social, and attitudinal environment in which people live and conduct daily life). Qualifiers to ICF codes indicate the extent or magnitude of an impairment in body function or structure (from no impairment to complete impairment) and the difficulty experienced in executing activities or participating in life situations (from no difficulty to complete difficulty). Environmental factors may serve as either a barrier or facilitator, with a scale from none to complete.

As illustrative examples, we added potential ICF codes to Tables 1, 2, and 3 to demonstrate how FSI might be coded using a con-

Table 4
Medicare Current Beneficiary Survey Question About Walking and Response Categories with Applicable ICF Codes¹

Question and Response Categories	ICF Codes
How much difficulty do you have walking a quarter of a mile (2 or 3 blocks)?	
Doesn't walk by self without special equipment.	d4500.4 walking short distances, complete problem
Unable to walk 2-3 blocks.	d4500.4 walking short distances, complete problem
A lot of difficulty.	d4500.3 walking short distances, severe problem
Some difficulty.	d4500.2 walking short distances, moderate problem
A little difficulty.	d4500.1 walking short distances, mild problem
No difficulty at all.	d4500.0 walking short distances, no problem

¹ Applicable *International Classification of Functioning, Disability and Health* (ICF) and *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) codes would record the underlying medical condition.

SOURCES: 1996 Medicare Current Beneficiary Survey; (World Health Organization, 2001; Centers for Disease Control and Prevention, 2003).

sistent classification scheme; ICF coding of such clinical tools requires further study. Nevertheless, these examples highlight several points. First, most levels of the functional status measures actually address more than one aspect of functioning. The clearest example is the New York Heart Association functional class, which explicitly encompasses fatigue, palpitations, dyspnea, and anginal pain within individual levels. Each of these four body functions receives a separate ICF code. Conceivably, the extent of functional impairments could vary across these four clinical signs for specific cardiac patients. Therefore, the ICF codes assigned to fatigue, exercise tolerance, cardiorespiratory sensations, and chest pain could give more information than the New York Heart Association functional class. Second, ICF codes with 0 after the decimal point indicate that the condition does not exist or is not a problem. Thus, ICF permits coding of both positive and negative clinical findings. Finally, ICF facilitates a crosswalk of identical concepts across functional status measures. For instance, both the Karnofsky Performance Status measure (Table 2) and EDSS (Table 3) address whether patients can carry out their daily routine (ICF code d230).

Using ICF codes, analysts could thus compare FSI generated in very different settings using different approaches. For instance, assigning ICF codes to the MDS, OASIS, and IRF-PAI data elements could facilitate comparisons of data generated by nursing homes, home health agencies, and rehabilitation hospitals. FSI generated directly by Medicare beneficiaries rather than by clinicians could also receive ICF codes. As an example, Table 4 contains the question about walking short distances and response categories from the Medicare Current Beneficiary Survey (MCBS), along with the applicable ICF codes. Tables 3 and 4 use identical ICF codes, although the data are generated through different measurement approaches (EDSS versus MCBS) and respondents (clinicians versus Medicare beneficiaries). ICF allows users to compare the FSI produced using these different approaches.

Adding ICF Codes to Administrative Data

Even if FSI were assigned ICF codes, administrative databases would still need to capture and store these codes, just as

they do ICD-9-CM, CPT, and other codes. The majority of administrative data within the U.S. health care system is electronic, generated and transmitted via computers. Different types of administrative functions or transactions, such as enrolling persons in health insurance plans or submitting claims for payment, are performed electronically using specialized formats. Utilizing common standards for these transaction formats allows diverse public and private organizations throughout the health care delivery system to communicate effectively and reduces the burden on providers. The Health Insurance Portability and Accountability Act (HIPAA) of 1996 contained important administrative simplification provisions to standardize transactions of critical health care functions, including the required message formats, data elements, identifiers, and code sets.

Over the last several years, the U.S. Department of Health and Human Services has promulgated transaction standards for billing and related administrative functions as mandated by HIPAA. These standards must be adopted by October 2003 by all payers and by all providers who bill electronically. Procedures for defining and modifying HIPAA-mandated standards are rigorous, imposing stringent requirements for changing or enhancing transaction standards and necessitating full support from the health care industry. Garnering this support demands a strong business case. Most transaction standards must pass through the American National Standards Institute (ANSI) Accredited Standards Committee (ASC) X12N, which has members from numerous public and private organizations. Any effort to add ICF codes to transaction standards will confront rigorous scrutiny.

The first step in considering adding ICF codes to transaction standards is to specify which transactions are most relevant.

Administrative databases generally draw from two transaction standards: (1) formats for enrolling persons into health insurance plans; and (2) reports on or claims for specific encounters or services received by individuals. Either transaction could potentially capture FSI. For example, significant ADL limitations could be identified during health plan enrollment (e.g., through questionnaires), then coded using ICF (e.g., codes could be linked to particular questionnaire responses). Functional status also could be assessed during individual health care encounters. The NCVHS (2001) recognized that defining when, where, how, and how often to capture ICF codes requires extensive study, looking not only at data collection burden and data quality, but also at whether special concerns arise about privacy.

Currently, the standard transaction format for health care encounters or claims does not accommodate routine capture of functional status in either inpatient or outpatient settings using ICF or other data elements.³ Another transaction format, the claim attachment, captures information on specific outpatient therapies; this could be adapted to collect ICF codes, although claim attachments apply only to designated therapies. The NCVHS (2001) recommended that organizations like ANSI and ASC X12N, which are responsible for maintaining encounter and claim transaction standards, "...should be alerted that NCVHS and the Department have a strong interest in the coding of functional status information in administrative records and computerized medical records."

Efforts are already underway to add new information to standard transaction formats. The Public Health Data Standards

³ An institutional standard specifically designed to transmit home health agency treatment plan information does contain indicators for the presence of approximately 12 conditions, such as ambulation problems, vision and hearing loss, and incontinence, without indicating the extent of related functional deficits.

Consortium (referenced hereafter as the Consortium), a coalition of 37 organizations committed to promoting data standards for public health and health services research, has developed and presented business cases to standards development organizations to improve health care information for assessing quality of care. The Consortium has worked with the ASC X12N to incorporate information in the claim/encounter transaction standard on patients' race and ethnicity, mother's medical record number (for newborn claims), and a qualifier indicating the timing of onset of secondary diagnoses. The Consortium has needed to demonstrate the value of the information to health care providers and plans, the feasibility of collecting it consistently, and the tradeoff between value and burden of collection. Educating members of relevant work groups and exploring the best way to collect the information demand considerable time.

In early 2001, the Consortium received approval from ASC X12N to develop a Health Care Service Data Reporting Implementation Guide (Public Health Data Standards Consortium, 2003) to promote public health reporting in a standardized way compatible, but not compliant with, the national data standards promulgated under HIPAA. Health plans and others will use this guide to collect several of the new data elements and could employ it to collect FSI as a pilot test prior to requiring it as a HIPAA standard. As previously discussed, the claim attachment standard offers opportunities for standardized collection of FSI on specialized patients. Consortium representatives participate in the Attachment Special Interest Group of Health Level Seven, a national committee developing the HIPAA Attachment Standards, including an attachment for rehabilitation services. The latter currently col-

lects functional status as free text information, which is inherently highly variable. Developers could explore using ICF codes to generate comparable information, as well as creating other attachment standards to capture ICF codes. Pursuing such approaches, which parallel national standards already adopted by the health care industry, lays the groundwork for future collection of ICF codes after research and demonstration studies of ICF are completed.

Utility of FSI

Finally, our initial argument for capturing FSI—to determine whether our health care system meets the goal of improving the "...functioning of the people of the United States..." (President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1998)—is admittedly abstract. Such a global purpose may not satisfy the need previously described for a strong business case to collect these potentially costly data. FSI must be used effectively, making important contributions to our health care delivery system, before it will be fully embraced. Because ICF coding has not been widely implemented in the U.S., no empirical evidence yet exists to document the value of adding ICF codes to administrative data sets. Therefore, conjectures about the potential utility of ICF remain speculative, and research is required to document the costs and benefits of ICF coding.

Based on expert testimony, the NCVHS (2001) suggested that population-level functional status data could productively inform five broad activities. First, as Medicare already does in post-acute and LTC, managers could use FSI to predict service utilization and resource use, adjust payments to account for patient need,

assess quality, and evaluate the outcomes of different treatment modalities and health care delivery interventions.

Second, quality improvement initiatives could use FSI to compare provider performance, identify best practices, and support quality improvement. Third, public health practitioners could use these data to evaluate progress toward improving population health, specifically meeting *Healthy People 2010* (U.S. Department of Health and Human Services, 2000) goals—increasing years of healthy life and eliminating population health disparities. Fourth, FSI could assist health policy leaders in setting priorities and allocating scarce resources. Finally, researchers could use this information to better understand the value of specific clinical interventions, as well as the impact of health policy and management decisions. Clouser and Bierman (2003) explore these types of concerns.

Although substantive empirical evidence about the administrative value of ICF is largely lacking, research using other FSI offers insights into the potential contributions of ICF-coded data. As previously noted, Medicare already pays nursing homes, home health agencies, and rehabilitation hospitals based largely on functional status, using resource utilization groups, and case-mix groups, respectively. But because the data systems differ across care settings, their relative costs and outcomes of care cannot be compared directly, although many patients are often similar across these three settings. Coding the data using ICF could theoretically facilitate such comparisons.

Research concerning setting capitated payment levels for health maintenance organizations or Medicare's managed care organizations (MCOs) has considered the value of adding FSI. Most research, however, has utilized functional status reports provided by patients, such as through the

MCBS (Adler, 1994) or Short Form 36 (SF-36) (McHorney et al., 1994; Stewart, Hays, and Ware, 1988), rather than generated by providers. Pursuant to mandates of the 1997 Balanced Budget Act, Medicare currently partially risk adjusts MCO payments, setting MCO reimbursements based on each enrollee's age and health status as indicated by principal diagnoses from hospitalizations (Iezzoni et al., 1998; Greenwald et al., 1998; Pope et al., 2000).⁴ Research on refining risk-adjusted MCO payments has examined whether functional status and other patient-reported information, alone or combined with data on diagnoses, improves predictions of costs for persons enrolled in MCOs.

Results have proved mixed. Some studies have found that self-reported FSI, gathered using SF-36 questionnaires (Hornbrook and Goodman, 1995, 1996) or through the MCBS (Gruenberg, Kaganova, and Hornbrook, 1996) substantially improves predictions over models using only demographic or diagnostic information. Others, however, have found that self-reported functional status performs less well than risk adjustment using diagnoses (Fowles et al., 1996; Pope et al., 1998). Most researchers agree that adding patient-reported FSI significantly enhances predictions of annual health care costs, but is insufficient alone. Instead, self-reported functional status and overall health complements more standard predictors—sociodemographic characteristics and diagnoses, especially chronic conditions (Gruenberg, Kaganova, and Hornbrook, 1996; Hornbrook, 1999). The focus then turns to strategies for gathering this information from health plan enrollees accurately and efficiently (Hornbrook, 1999), which is logistically challenging and potentially costly.

⁴In the future, Medicare plans to set MCO payment levels based on diagnoses regardless of setting of care.

Assessing provider performance using functional status measures has generated less research than risk adjusting payments, but Medicare's Health Outcomes Survey (HOS) is perhaps the largest example. The HOS aimed: "...(i) to monitor health care quality in an ongoing standardized way; (ii) to provide information about quality to Medicare beneficiaries to assist them in choosing between different managed care plans; and (iii) to provide further incentive for quality improvement..." (Cooper et al., 2001). Medicare MCOs must contract with designated vendors to gather HOS health status information from sampled MCO enrollees at one time point, then again 2 years later (National Committee for Quality Assurance, 2003). Vendors collect the data using mailed questionnaires, with telephone followup of non-respondents. The difference in self-reported health status between years 1 and 3 is the change score, the quality indicator to be reported for each MCO.

The first HOS surveys were fielded in May 1998 in a sample of almost 280,000 Medicare members across 268 health plans, generating more than 167,000 responses (Centers for Medicare & Medicaid Services, 2002d). The followup survey in 2000 produced roughly 75,000 responses across 195 health plans. Results have yet to be released publicly.

Although some hail it as a visionary effort to use patient outcomes to monitor quality and motivate improvement, the HOS raises important questions (Cooper, 1998; Cooper et al., 2001; Golden, 2001; Safran, 2001). Perhaps most notable is the question of attribution: whether decrements or improvements in self-reported physical and mental functioning can really be attributed to actions of MCOs.

"A strong and consistent relationship between patient-reported health status and health care has yet to be demonstrated. In

fact, the application of general health status measures to the evaluation of the 'effectiveness' and 'quality' of medical care has yielded a mixed and confusing picture. ... It is one thing to assess the health of a community or population, the purpose for which general health status measures were originally intended. It is [a] very different problem to investigate the relationship of an individual's perception of his or her health to structural features or specific processes of medical care. ... The measurement community has been slow to accept that in most instances, medical care has only an indirect and a rather small effect on such outcomes." (Kaplan, Kravitz, and Greenfield, 2000.)

Many technical issues remain, such as the impact of differential response rates across MCOs (the 1998 questionnaire found 29 to 79 percent response rates across MCOs [Cooper et al., 2001]). Many factors influence response rates, including health and cognitive status, literacy and language, and willingness to participate. One emerging concern may be fear of breaching privacy.

"HOS surveys require an individual beneficiary to reveal considerable personal information about themselves and their health. The linking of an individual's health perceptions to an administrative database could provide a powerful window on the effectiveness of the health care system. It also ... could be used to assist insurance entities in selecting a population whose medical risks make future expenditures more predictable. [Such in-depth] personal profiles ... have chilled privacy experts." (Golden, 2001.)

Although these research studies on risk-adjusting payment and evaluating outcomes of care have relied on self-reports generated by patients or survey respondents, they hold implications for ICF-coded information from providers. Additional

research is clearly needed to determine the utility of FSI, especially in coded formats, for managing and evaluating the performance of the health care system. This research is only possible if comparable FSI is more routinely available from multiple health care settings. The absence of such information represents a significant gap in what we know about people's health care needs and their responses to interventions.

CONCLUSIONS

The importance of questions relating to functional status will grow in coming decades. Recent reports suggest that rates of functional deficits are declining among older persons (Manton, Corder, and Stallard, 1997; Manton and Gu, 2001; Cutler, 2001), although evidence concerning the most severe debilities is contradictory (Freedman, Martin, and Schoeni, 2002). Nevertheless, with the aging population, the absolute number of Americans with functional limitations will rise by at least 311 percent by 2049 if the age-specific prevalence of major chronic conditions remains unchanged (Boult et al., 1996). Providing services and organizing care to maximize functional independence—the physical, sensory, and cognitive ability to perform daily activities in homes and throughout communities—will therefore become increasingly important. Social policies beyond the health care system will also need to consider functional concerns, such as ensuring better accessibility of housing and transportation.⁵

Making sure that our expensive health care system achieves its goals of improving health and functioning will therefore become even more challenging in the future. The health care system currently fails many, especially persons with chronic

and disabling conditions (Institute of Medicine, 2001a). Adding FSI to routinely collected administrative data could provide an essential tool for managing and monitoring the future performance of the health care system, especially for subpopulations excessively burdened by chronic disease and functional deficits. We clearly need better ways to quantify the deficiencies of health care and to track the consequences of systemwide changes. Nevertheless, adding FSI to routinely collected administrative data requires careful study and testing. Ultimately, policymakers, payers, and providers will need to agree that the value of collecting FSI outweighs the costs.

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⁵ For example, the 1999 *Olmstead Decision* by the Supreme Court requires Federal, state, and local governments to develop more accessible systems of care and integrate services for individuals with disabilities into the community.

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