ARE THE STARS ALIGNING FOR ICF IN THE UNITED STATES?

Lisa I. Iezzoni, MD, MSc
Institute for Health Policy
Massachusetts General Hospital
Harvard Medical School
June 10, 2009
Thanks to John Hough and Marjorie Greenberg
U.S. health care system could not function without coded data.
CODED DATA

• Health care delivery requires:
  - Diagnosis codes
  - Procedure codes

• Codes used to determine:
  - Payment levels (MS-DRGs, HCCs for Medicare Advantage plan payment)
  - Quality metrics (mortality rate risk adjustment)
  - Monitor service use, cost patterns
  - Monitor public health concerns
International Classification of Diseases
9th Revision-Clinical Modification

ICD-9-CM
for Hospitals & Payers

Volumes 1, 2 & 3

2008
ICD

- ICD-9-CM adopted in 1979
- In 2009, ICD-9-CM has limitations
- Most other countries have moved to ICD-10
Need to know more about how persons are functioning, participating in activities of daily life.
2001 ICF ENDORSEMENT

• 54th World Health Assembly (WHA54.21)
• Universal endorsement for:
  – Research
  – Surveillance
  – Reporting
• “As appropriate in Member States”
• Children and Youth Version (ICF-CY) 2007
ICF has never gained traction in the United States.
What are key leverage points?
ALIGNING FORCES

1. Social forces
2. Demographic forces
3. Consequences of health care reform
   • Monitoring and maintaining quality of care
   • Health information technology (HIT)
4. Public health focus on determinants of health
   • Disparities in health and health care
5. Growing recognition of ICF in U.S.
The concept of functional status ... applies to all persons, regardless of age, physical or mental condition, or other characteristic.

NCVHS Report, 2001, p. 3
Societal Forces
“Disability is a lonely state.”
Accommodations require that disability be known and noticed.
Code in a medical record could alert staff to patient’s needs.
Demographic Forces
Across the life span, Americans are living with growing numbers of chronic conditions and disabilities.
EPIDEMIOLOGY

- 40-54 million Americans
- Disability rates rise with age
  - 5-15 years: 6%
  - 16-20 years: 7%
  - 21-64 years: 13%
  - 65-74 years: 30%
  - 75+ years: 53%
Number of people age 65 and over, by age group, selected years 1900–2006 and projected 2010–2050

Note: Data for 2010–2050 are projections of the population.
Reference population: These data refer to the resident population.
Life expectancy at ages 65 and 85, by sex, selected years 1900–2004

Reference population: These data refer to the resident population.
Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System.
Disease and disability are distinct concepts, although they often coexist.
CAUSAL LINKS

• Disease frequently contributes to disability
  – Osteoarthritis → impaired walking
  – Diabetes → vision problems

• Disability can cause new diseases
  – Spinal cord injury → urosepsis, pressure ulcer

• Chronic conditions → rising disability prevalence among Americans
  – Arthritis (#1), back problems (#2), heart troubles (#3)
AGING-RELATED IMPAIRMENTS

• Vision: presbyopia, glaucoma, macular degeneration
• Hearing: presbycusis
• Cognitive function: Alzheimer’s, organic brain dysfunction
• Physical function: arthritis, back problems, diabetes, stroke, cardiorespiratory diseases, etc.
Percentage of people age 65 and over who reported having selected chronic conditions, by sex, 2005–2006

<table>
<thead>
<tr>
<th>Condition</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart disease</td>
<td>37</td>
<td>26</td>
</tr>
<tr>
<td>Hypertension</td>
<td>52</td>
<td>54</td>
</tr>
<tr>
<td>Stroke</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Asthma</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Chronic bronchitis or Emphysema</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>Any cancer</td>
<td>24</td>
<td>19</td>
</tr>
<tr>
<td>Diabetes</td>
<td>19</td>
<td>17</td>
</tr>
<tr>
<td>Arthritis</td>
<td>43</td>
<td>54</td>
</tr>
</tbody>
</table>

Note: Data are based on a 2-year average from 2005–2006.
Reference population: These data refer to the civilian noninstitutionalized population.
Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey.
Percentage of people age 65 and over who reported having any trouble hearing, any trouble seeing, or no natural teeth, by sex, 2006

Note: Respondents were asked “Which statement best describes your hearing without a hearing aid: good, a little trouble, a lot of trouble, deaf?” For the purposes of this indicator the category “Any trouble hearing” includes “a little trouble, a lot of trouble, and deaf.” Regarding their vision, respondents were asked “Do you have any trouble seeing, even when wearing glasses or contact lenses?” The category “Any trouble seeing” also includes those who in a subsequent question report themselves as blind. Lastly, respondents were asked, in one question, “Have you lost all of your upper and lower natural (permanent) teeth?”

Reference population: These data refer to the civilian noninstitutionalized population.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey.
Percentage of Medicare enrollees age 65 and over who are unable to perform certain physical functions, by sex, 1991 and 2005

Note: Rates for 1991 are age adjusted to the 2005 population.
Reference population: These data refer to Medicare enrollees.
Source: Centers for Medicare and Medicaid Services, Medicare Current Beneficiary Survey.
“The ‘baby boomers’ are coming. We’re not going to warehouse them in nursing homes. These ‘boomers’ are not going to go quietly into the night.”
“... Disability in America is not a minority issue ... Disability affects today or will affect tomorrow the lives of most Americans ... People born in 1946 will turn age 65 in 2011. The future of disability in America will ... depend on the country’s response to this demographic shift.”

*Future of Disability in America 2007*
Health Care Reform
HEALTH CARE AND THE “FIERCE URGENCY OF NOW”

“Our families will never be secure, our businesses will never be strong, and our Government will never again be fully solvent until we tackle the health care crisis.”
President Bill Clinton, State of the Union Address, February 17, 1993
President Barack Obama
This year, we must do more than discuss. We must act. ... America’s future demands it.

Obama, June 2, 2009
$2.4 trillion
Without a serious, sustained effort to reduce the growth rate of health care costs, affordable health care coverage will remain out of reach.

Obama, June 2, 2009
Estimated Contributions of Selected Factors to Long-Term Growth in Real Health Care Spending per Capita, 1940 to 1990

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Aging of the Population</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Changes in Third-Party Payment</td>
<td>10</td>
<td>13</td>
<td>10</td>
</tr>
<tr>
<td>Personal Income Growth</td>
<td>11-18</td>
<td>5</td>
<td>&lt;23</td>
</tr>
<tr>
<td>Prices in the Health Care Sector</td>
<td>11-22</td>
<td>19</td>
<td>Not Estimated</td>
</tr>
<tr>
<td>Administrative Costs</td>
<td>3-10</td>
<td>13</td>
<td>Not Estimated</td>
</tr>
<tr>
<td>Defensive Medicine and Supplier-Induced Demand</td>
<td>0</td>
<td>Not Estimated</td>
<td>0</td>
</tr>
<tr>
<td>Technology-Related Changes in Medical Practice</td>
<td>38-62</td>
<td>49</td>
<td>&gt;65</td>
</tr>
</tbody>
</table>
Sources of Growth in Projected Federal Spending on Medicare and Medicaid: CBO Projections
• Obama’s strategy: address roots of 1994 failure of Clinton’s initiative
• Give Congress broad principles about what plan must have
• Involve all stakeholders as much as possible (e.g., insurers, consumers)
• Let Congress do hard work of negotiating plan
PRINCIPLES #1

1. Protect financial health of families
2. Make health insurance affordable
3. “Aim for” universality (uneasy about mandates)
4. Make coverage portable
PRINCIPLES #2

5. Guarantee choice
6. Invest in prevention and wellness care
7. Improve patient safety and quality of care
8. Maintain long-term financial sustainability
INSTITUTE OF MEDICINE

CROSSING THE QUALITY CHASM

A New Health System for the 21st Century
QUALITY EDICT

- Demands data: cannot manage what cannot measure
- Diagnostic and procedural data only go so far
- Need to know patients’ functional status
- Ideally also need to know patients’ preferences for care
RISK ADJUSTMENT

- 30-day, post-admission mortality
- Age, sex
- History of PTCA, CABG, heart failure, MI
- Secondary diagnoses from admission: e.g., diabetes, metastatic cancer, COPD, dementia, protein-calorie malnutrition
These percentages were calculated from Medicare data on patients discharged between July 2006 and June 2007. They do not include people in Medicare Advantage (managed care) plans or people who do not have Medicare.

**Heart Failure 30-Day Mortality**

*Adjusted Death Rate*

<table>
<thead>
<tr>
<th>7%</th>
<th>8%</th>
<th>9%</th>
<th>10%</th>
<th>11%</th>
<th>12%</th>
<th>13%</th>
</tr>
</thead>
</table>

Lower Percentages Are Better

**National 30-Day Death Rate from Heart Failure = 11.1%**

MASSACHUSETTS GENERAL HOSPITAL

9.3%

No different than National Rate

Number of Medicare Heart Failure Patients: 348

Range of uncertainty around estimated death rate (*“Interval estimate”*).

**Legend**

$x\%$ ← Estimated death rate (risk-adjusted)

**What does this show you?** The graph above shows the estimated 30-day death (mortality) rates for heart failure at each of the hospitals you selected, compared to the national 30-day death rate for all Medicare patients treated for heart failure. The death rates for each hospital shown here have been Risk-Adjusted. This means that they take into account how sick patients were before they were admitted to the hospital.
RISK ADJUSTMENT ?’s

• New York Heart Association Functional Class = critical indicator of risk in heart failure
• ICF codes could convey that information
• Full information on patients’ risks required to avoid penalizing hospitals with sicker patients
HOSPICE QUESTIONS

- Buffalo, NY, hospital: among worst 35; CHF mortality 4.9% higher than national average (Holloway & Quill, *JAMA* 2007)
- 40% of CHF deaths: DNR, hospice
- Mortality model did not account for DNR, hospice care
HEALTH INFORMATION TECHNOLOGY (HIT)

- $20 million to National Institute of Standards and Technology to work on technical standards, etc.
- “Qualified electronic health record”
  - “Improves health care quality, reduces medical errors, reduces health disparities, and advances delivery of patient-centered care”
ARRA REQUIRES HIT TO:

• Reduce “health care costs resulting from inefficiency, medical errors, inappropriate care, duplicative care, and incomplete information”

• Provide “appropriate information to help guide medical decisions at the time and place of care”
Information on functional status must become an integral part of electronic health record.
Can ICF be integrated within standard electronic data elements?

2005-2006 work of Consolidated Health Informatics (CHI) initiative
  – Phase II Disability Work Group efforts

CHI Functioning and Disability Domain; use LOINC® → ICF codes

NCVHS Report, November 2006
“Endorsing ICF as a CHI standard for ... functioning and disability:
- Inclusion of ICF in UMLS
- Mapping between ICF and SNOMED
- Expanding coded disability content available for use
- Making ICF available for use ... in standardizing patient assessments ...”
POST-ACUTE CARE

• Nursing homes: Minimum Data Set (MDS)
• Home health agencies: Outcome and Assessment Information Set (OASIS)
• Inpatient rehabilitation facilities: Patient Assessment Instrument (IRF-PAI)
Public Health
Healthy People 2010

Volume I

- Understanding and Improving Health
- Objectives for Improving Health
  (Part A: Focus Areas 1-14)
Action Model to Achieve Healthy People 2020 Overarching Goals

Determinants of Health

- Broad social, economic, cultural, health, and environmental conditions
- Living and working conditions
- Social, family, and community network
- Individual behavior

Interventions
- Policies
- Programs
- Information

Outcomes
- Behavioral outcomes
- Specific risk factors, diseases, and conditions
- Injuries
- Well-being and health-related Quality of Life
- Health equity

Assessment, Monitoring, Evaluation & Dissemination
Broad social, economic, cultural, health, and environmental conditions and policies at the global, national, state and local levels ...
Healthy People 2010

Volume I
- Understanding and Improving Health
- Objectives for Improving Health
  (Part A: Focus Areas 1-14)
The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities 2005

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Office of the Surgeon General
Rockville, MD
BREAST CANCER

- Breast conserving surgery (BCS) for early-stage breast cancer; requires radiation therapy after surgery
- Women with disabilities < age 65:
  - 20% less likely to get BCS
  - If they have BCS, 17% less likely to get radiation therapy
  - 45% more likely to die from breast cancer

Annals Intern Med 2006
CANCER REGISTRY

- Surveillance, Epidemiology, and End Results (SEER) cancer registries, produced by NCI – merged with Medicare claims
- Clinical information on tumor type and characteristics, treatments
- Nothing on functional status, although oncologists focus on functional status to make treatment decisions: used SSDI
DISPARITIES REPORT

- 1999 Congressional mandate to Agency for Healthcare Research and Quality (AHRQ)
- Report on “prevailing disparities in health care delivery as it relates to racial factors and socioeconomic factors in priority populations”
- Includes people with disabilities
2007 CONTENT

- Exercise counseling: obese adults
- Inappropriate medication use by elderly
- Delay receiving needed care
- Children with special health care needs
  - Delays in care for illness, injury
  - Poor communication with health care providers reported by parents
REPORT LIMITATIONS

• Limited definitions of disability
• Relied largely on self-reported ADL limitations
  – Basic activity limitations
  – Complex activity limitations
• Few reported measures
Growing Recognition
NCVHS REPORTS

• “Classifying and Reporting Functional Status” (2001)
  – “ICF is the only existing classification system that could be used to code functional status across the age span” (p. 13)

• “Consolidated Health Informatics Standards Adoption Recommendations: Functioning and Disability” (2006)
  – “ICF is a CHI-endorsed standard for the functioning and disability domain” (p. 8)
UNIFIED MEDICAL LANGUAGE SYSTEM

• UMLS National Library of Medicine
• 2009: ICF and ICF-CY terms incorporated into UMLS Knowledge Systems
• Partnership with WHO
• UMLS user can link ICF terms with other classifications, terminologies, vocabularies within UMLS
OTHER EXAMPLES

- National Institute on Disability and Rehabilitation Research (NIDRR)
  - Incorporated ICF into NIDRR Logic Model and referenced ICF in defining disability
- Endorsements by ≈ dozen professional organizations
- *Healthy People 2010 (2000)*: Chapter 6 cited conceptual framework of earlier draft of ICF (ICIDH)
RECOMMENDATION 2.1

• NCHS, Census, Bureau of Labor Statistics and others should adopt ICF conceptual framework
• Promote refinements and improvements of ICF
• Interagency Committee on Disability Research
DIRECTIONS

1. Clarify activity and participation concepts
2. Incorporate quality of life
3. Delineate personal factors
4. Extend classification of environmental factors
5. Incorporate secondary health conditions
6. Add dynamic model reflecting movement across functional states
Rationale and impetus are building – must seize the moment