National Center for Health Statistics



Status on ICD-11: The WHO Launch

Donna Pickett,
Chief, Classifications and Public Health Data Standards
Head, Collaborating Center for the WHO-FIC in North America

Robert N. Anderson, PhD
Chief, Mortality Statistics Branch
Division of Vital Statistics

National Committee on Vital and Health Statistics
July 18, 2018

ICD Revision History (Mortality and Morbidity)

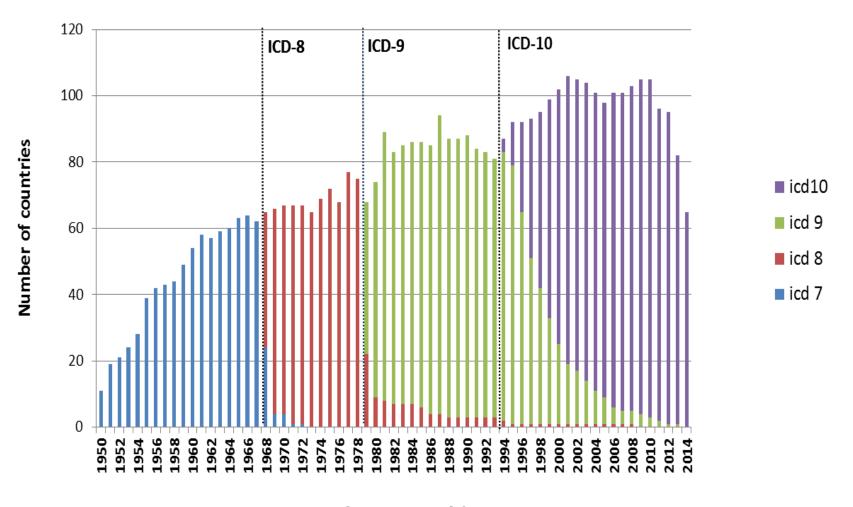
| ICD Revision No. | Year of Conference When Adopted | Year in Use in the U.S. Mortality | ICD, Clinical Modification Morbidity | Year in Use in the U.S. |
|---------------------|--|---|--|-------------------------------------|
| First | 1900 | 1900-1909 | | |
| Second | 1909 | 1910-1920 | | |
| Third | 1920 | 1921-1929 | | |
| Fourth | 1929 | 1930-1938 | | |
| Fifth | 1938 | 1939-1948 | | |
| Sixth | 1948 | 1949-1957 | | |
| Seventh | 1955 | 1958-1967 | | |
| Eighth | 1965 | 1968-1978 | ICDA-8 H-ICDA-1 H-ICDA-2 | 1968-1978 1968-1972 1973-1978 |
| Ninth | 1975 | 1979-1998 | ICD-9-CM | 1979 |
| Tenth | 1989 | 1999- | ICD-10-CM | Oct. 1, 2015 |

Needs and Uses: Mortality statistics



- Mortality by age, sex, and cause of death is the foundation of public health, globally and in countries: comparable mortality statistics over time
- Sustainable Development Goals (SDG) 2016-2030: nearly a dozen mortality by-cause targets and indicators (NCD, suicide, violence, environmentally related, maternal, etc.)

Trends in cause-of-death reporting by ICD revision



Reference year of data

Needs and Uses: Morbidity Statistics



- Morbidity statistics (incidence, prevalence, sequelae) are also an essential foundation for public health
- Morbidity statistics are much less widely applied
 - Fully implemented in 41 countries
 - Partially implemented in 6 countries
- Comparative morbidity statistics are often lacking
 - based on special surveillance systems, with limitations (e.g. HIV, TB, cancer)
- Need for simplified lists and tools

Other needs and uses of ICD



- Administrative tool
 - Used for reimbursement and resource allocation in significant number of countries;
 - National clinical modifications in almost 30 countries
- Clinical research
- Monitoring specific areas
 - Health care quality and safety: health-care associated adverse events including AMR
 - Primary care
 - Surveillance and identification of reportable events

ICD-10



- Approved by World Health Assembly in 1989
- Tabular List published in 1992;
 Index published in 1994
- Implemented in the US for mortality in 1999
- Updated periodically
 - Minor updates every year
 - Major updates every three years

ICD-10

The International Statistical Classification of Diseases and Health Related Problems

Tenth Revision

Volumen 1

PAN AMERICAN HEALTH ORGANIZATION
Pan-American Sanitary Office, Regional Office of
THE WORLD HEALTH ORGANIZATION

ICD-10 in 2018



- Translated into **43** languages
- Used in over 100 countries, including more than 2 dozen modifications
- Basis for global cause-specific mortality statistics
- But now >25 years old



The International Statistical Classification of Diseases and Health Related Problems

Tenth Revision

Volumen 1

PAN AMERICAN HEALTH ORGANIZATION
Pan-American Sanitary Office, Regional Office of
THE WORLD HEALTH ORGANIZATION



Need for an 11th Revision

- Substantial advancements in medicine and the science of disease have occurred over the past 30 years
 - ICD-10 is outdated both clinically and from a classification perspective
 - Substantial structural changes were needed to some chapters
 - Changes could not be handled under the normal ICD-10 updating mechanism
 - Changes needed were well beyond a major update
- Increasing need to operate in an electronic environment
- Need to capture more information, especially for morbidity use cases
- Decision was made in 2007 to begin work on ICD-11

ICD-11: Revision Impetus



- Capture advances in health science and medical practice
- Make better use of the digital revolution
- Better address multiple topics; e.g. quality & safety, traditional medicine, etc.
- Address persistent major gaps in basic use for mortality statistics

- Improve morbidity statistics
- Easier use
- Manage national clinical modifications in more effective manner
- Improve integration of other classifications and terminologies
- Improve comparability of translations



ICD-11 Revision Goals

- Ensure that ICD-11 will function in an electronic environment
 - Digital product
 - Link with terminologies (e.g., SNOMED) and other classifications
 - Support electronic health records and information systems
- Multi-purpose and coherent classification
 - Mortality, morbidity, primary care, clinical care, research, public health...
 - Consistency and interoperability across different uses
 - International multilingual reference standard for scientific comparability (Arabic, Chinese, English, French, Russian, Spanish)

Better integration with other classifications

OTHER REFERENCE Classifications

International Classification of Functioning, Disability, & Health

International Classification of Health Interventions

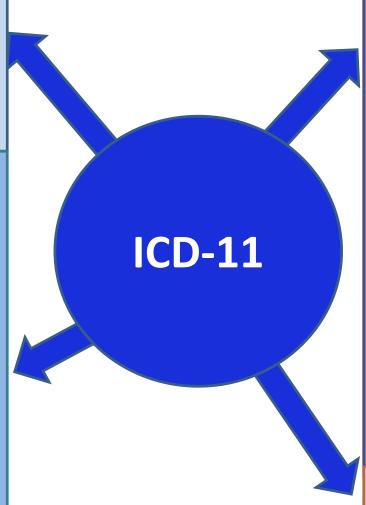
RELATED Classifications

International Classification of Primary Care (ICPC)

International Classification of External Causes of Injury (ICECI)

The Anatomical, Therapeutic, Chemical (ATC) classification system with Defined Daily Doses (DDD)

ISO 9999 Technical aids for persons with disabilities – Classification and Terminology



DERIVED Classifications

International Classification of Diseases for Oncology, Third Edition (ICD-O-3)

The ICD-10 Classification of Mental and Behavioural Disorders

Application of the International Classification of Diseases to Dentistry and Stomatology, 3rd Ed.(ICD-DA)

Application of the International Classification of Diseases to Neurology (ICD-10-NA)

ICF, Children & Youth Version (ICF -CY)

Terminologies

e.g. SNOMED-CT

ICD-11: the revision process



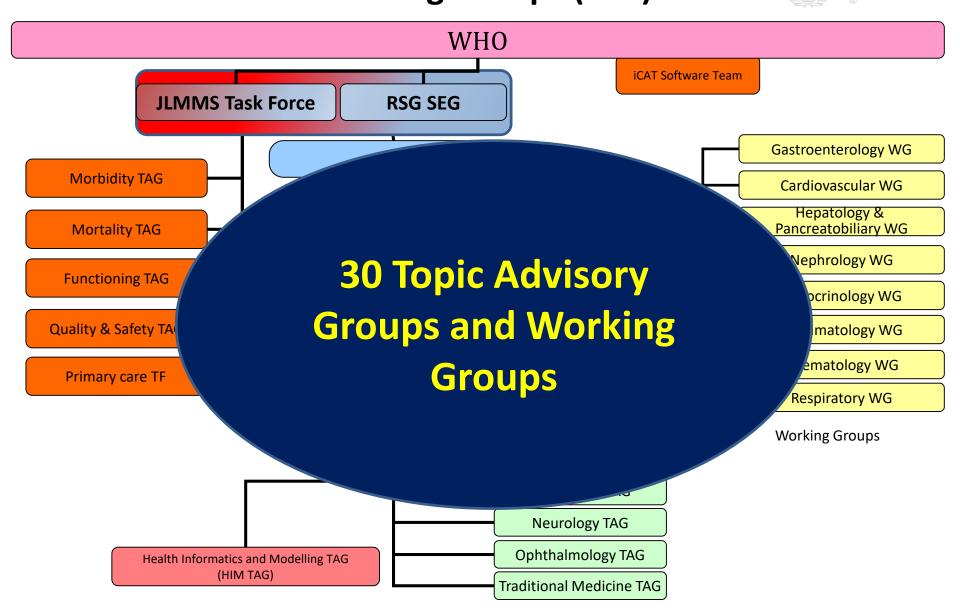
- Largest revision enterprise ever
- Internet platform for inputs and collaborative authoring platform (iCAT)

More than
10000 proposals
received

- Hundreds of scientists / clinicians have contributed
- More than 90 countries have been involved in production, reviews, testing or commenting

All processed*
(2 pending feedback)

ICD Revision: Web of Topic Advisory Groups (TAGs) and Working Groups (WG)



ICD -11: what's new



Tabular Lists

Fit for a particular purpose: reporting mortality, morbidity, or other uses

Entities of the foundation become categories that are *Jointly Exhaustive* and *Mutually Exclusive* of each other

New Contents – 27 Chapters

In several instance, new chapters:

- Disorders of the Immune system
- Dis. of blood & blood forming organs
- Conditions related to Sexual Health
- Sleep-wake disorders
- Traditional medicine
- Extension codes

New methods

- Precoordination and stem codes
- Post-coordination (<u>optional</u> extension codes)
- Sanctioning rules
- Multiple parenting
- Linearizations

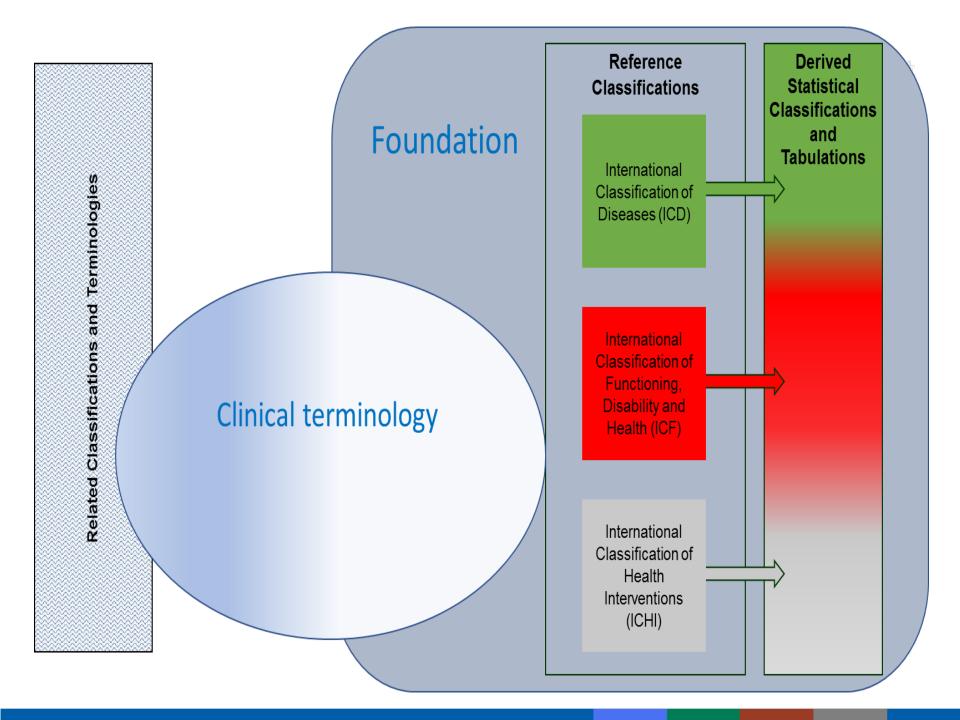
New and improved tools

- Coding tools
- Browsing tools
- Translation tools
- Mapping tool
- Proposal tool

ICD Revision Process



- External review in 2015
- Phase 1: until 2015: extensive clinical inputs from TAGs and methodological work to meet the many uses
- Phase 2: from April 2015 to present: focus on mortality and morbidity statistics (MMS)
- <u>Phase 3</u>: from now until May 2019: preparations for implementation version
- Phase 4: thereafter: Maintenance



Statistical review and Joint Task Force 2018



- Overall structure of ICD-11 was presented and reviewed, chapter by chapter → ready to be released
 - Some small corrections were suggested
 - Need additional user guidance in some places
- Updated mortality coding rules reviewed → ready to be used
 - Improvements in wording suggested
 - Some clarifications by Mortality Reference Group made
 - Usage of code combinations for the underlying cause of death is desirable, but feasable only in some settings
 - Multiple cause analysis relevant in aging populations is desirable, but feasable only in some settings



Foundation

- Represents the knowledge base for the reference and derived classifications
- Constantly changing in response to advances in science and medicine
- Flexibility
 - Multiple classifications and tabulation lists can be derived from the foundation
- Consistency
 - All derived classifications will be consistent in terms of the knowledge base



Foundation: Content Model

- 1. ICD Concept Title
- 2. Classification Properties
- 3. Textual Description
- 4. Terms
 - 4.1 Base Index Terms
 - 4.2 Inclusion Terms
 - 4.3 Exclusions
- 5. Body Structure Description
 - 5.1 Body System(s)
 - 5.2 Body Part(s) [Anatomical Site(s)]
 - 5.3 Morphological Properties
- **6.** Manifestation Properties
 - 6.1 Signs & Symptoms
 - 6.2 Investigation findings

- 7. Causal Properties
 - 7.1 Etiology Type
 - 7.2 Causal Properties Agents and Mechanisms
 - 7.3 Risk Factors
 - 7.4 Genomic Linkages
- 8. Temporal Properties
 - 8.1 Biological sex
 - 8.2 Life-cycle properties
- 9. Severity of Subtypes Properties
- **10.** Functioning Properties
- 11. Specific Condition Properties
 - 11.1 Biological sex
 - 11.2 Life-cycle properties
- **12.** Treatment Properties
- 13. Diagnostic Criteria



ICD-11-MMS

- MMS = Mortality and Morbidity Statistics
- Derived from the foundation component
- Incorporating advances in science and medicine
- Structural consistency with ICD-10 where possible

ICD-11 MMS

International
Classification of
Diseases
for Mortality and
Morbidity Statistics



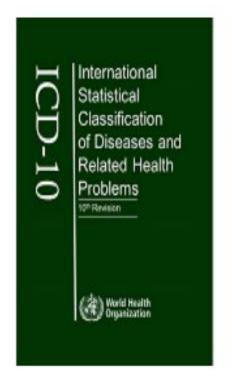
Examples of problems solved with ICD-11

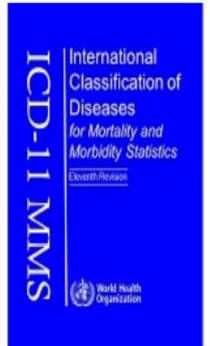


- Antimicrobial resistance essentially missing in ICD-10
- HIV subdivisions outdated detail in ICD-10
- Simplified Diabetes coding
- Skin cancer melanoma types missing basalioma missing in ICD-10
- Valve diseases outdated structure, need by valve, less rheumatic
- Postprocedural conditions clarify when use 19 and when not for postprocedural
- Cancers with histopathology ICD-O for cancer registries embedded
- External causes better coding traffic accidents

Major differences between ICD-10 and Wild Health ICD-11

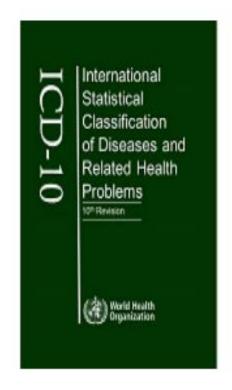
- Codes look different
 - Alzheimer disease
 - ICD-10 G30
 - ICD-11 8A20
- Simplified code structure
 - Extension codes (e.g., temporality, severity, dimensions of injury and external causes)
 - Clustering of codes combining 2 or more codes to describe a diagnostic entity

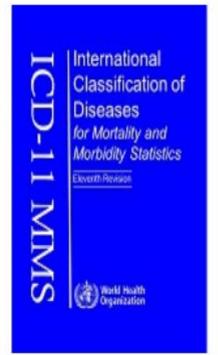




Major differences between ICD-10 and CD-11

- Some diseases have changed location
 - E.g., Cerebrovascular diseases moved from circulatory to nervous system chapter
- 6 new chapters
 - Diseases of blood and blood forming organs
 - Disorders of the immune system
 - Conditions related to sexual health
 - Sleep-wake disorders
 - Extension codes
 - Traditional medicine





ICD-11 IT friendly



- Web services full functionality available in the software of choice
- Online services everyone can use ICD without any local software
- Offline services all functionality available on a local computer with updates when internet is available
- Output files formats include CSV, Excel, ClaML, and others as necessary
- <u>Print version</u> Real paper version gives the look and feel of the past

ICD-11 – Implementation Package



- Advocacy materials
- Training materials
- Quick guide
- Maps from and to ICD-10 (transition tables)
- Training and test platform

Process of agreeing and adopting ICD-11



- **Step 1** was the formulation of ICD-11 over the past several years, with input from **international working groups** with more than 300 specialists from over 270 institutions in 55 countries of all regions.
 - This included clinical specialty NGOs, research institutions, centres nationally responsible for maintenance of ICD, and international data analysts of other departments of WHO, contributors to WHO reporting and treatment of diagnostic standards, and others.
 - In addition, there is the proposal platform where anyone can propose changes (based on documented evidence), discuss proposals and monitor processing of proposals. (so far, some 10000 have been processed)
- Step 2 invited comments from Member States, technical consultations in regions and field trials. (added another 40 countries to the process)
 - All input has been received and processed the majority incorporated, following consultation with the Medical Scientific Advisory Committee for ICD and the Joint Task Force for ICD-11. This task force is composed of specialists from different countries that work with ICD and are aware of the needs in coding and analysis for mortality and morbidity.
 - Morbidity includes epidemiology, casemix, and primary care. In primary care we collaborate closely with WONCA.

Process of agreeing and adopting ICD-11 (2)



- Step 3 will be the release of the version for implementation in June.
 - Feedback from start of preparations for implementation by Member States will serve to improve user guidance. From this June release on, the classification is stable, and the set of categories is considered complete. A release of such a version was not possible earlier, because the input received from testing and Member States needed to be incorporated.
- Step 4 will see a summary report that is submitted to the EB 144, January 2019.
 - The report will be based on the outcomes of the statistical meeting this April, the Joint Task Force for the ICD-11 revision meeting and the meeting of the Classifications and Statistics Advisory Committee that will also support WHO in the future maintenance of ICD, and the other classifications of the family.
 - Based on the report the EB would recommend ICD-11 submission to the Health Assembly for adoption.
- Step 5 is submission of ICD-11 through the EB to the World Health Assembly in May 2019 to come into effect on 1 January 2022

Way forward



- Maintenance and updates
 - Governance WHO-FIC Network
- Development of new tools
 - e.g. mobile coding
 - Ongoing crosswalks, i.e. SNOMED-CT
- Country support
 - Workshops and integration of tooling



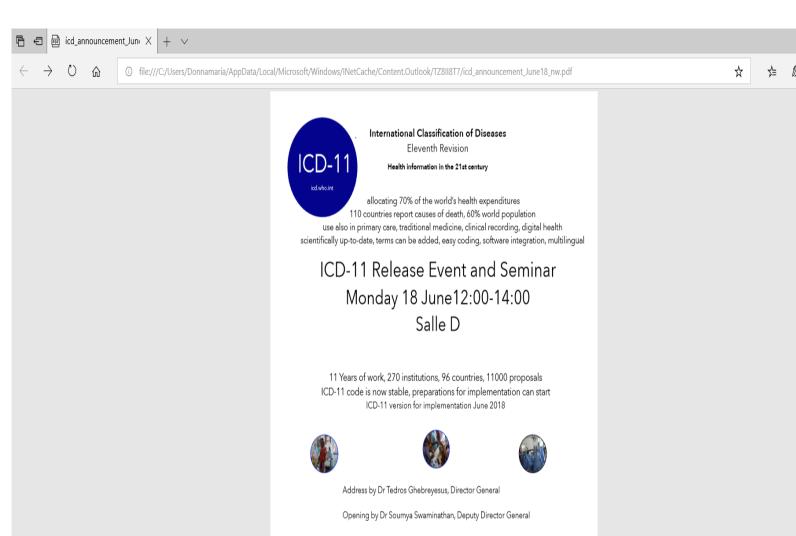
Classifications and Statistics Advisory Coclassmmittee (CSAC)



icd.who.int

With participation by

| Albania | Chile | Estonia | Indonesia | Lao | Nepal | Republic of Korea | Sweden |
|------------|-----------------------|-----------|-----------|------------|-------------|-----------------------|------------------------|
| Algeria | China | Ethiopia | Iran | Latvia | Netherlands | Russian Federation | Switzerland |
| Argentina | Colombia | Fiji | Iraq | Lebanon | New Zealand | Rwanda | Syria |
| Australia | Congo | Finland | Ireland | Libya | Nicaragua | Saudi Arabia | Tanzania |
| Austria | Costa Rica | France | Israel | Lithuania | Nigeria | Serbia | Thailand |
| Bangladesh | Cuba | Germany | Italy | Malawi | Norway | Singapore | Trinidad and Tobago |
| Belgium | Czech Republic | Ghana | Jamaica | Malaysia | Oman | Slovakia | Tunisia |
| Bolivia | Denmark | Guatemala | Japan | Mauritius | Panama | Slovenia | Turkey |
| Botswana | Dominican Republic | Guyana | Jordan | Mexico | Paraguay | South Africa | Turkmenistan |
| Brazil | Ecuador | Honduras | Kenia | Mozambique | Peru | Spain | Uganda |
| Cambodia | Egypt | Hungary | Kenya | Myanmar | Philippines | Sri Lanka | United Kingdom |
| Canada | El Salvador | India | Kuwait | Namibia | Poland | Surinam | USA Zambia |



Message by Dr Lubna Alansari, Assistant Director General HMM

Presenters include:

Dr Hiroyuki Suenaga Vice President Japan Heapital Association

Dr Christopher G. Chute

Bloomberg Distinguished Professor of Health Informatics Professor of Medicine, Public Health, and Nursing Chief Research Information Officer, Johns Hopkins Medicine

Deputy Director, Institute for Clinical and Translational Research

Dr Shekhar Saxena Director mental, neurological and substance use disorders Topics

ICD-11 Modern use of health information and informatics

ICD-11 - what is new ICD-11 and Mental health - gaming

ICD-11 Maternal and sexual health - gender Implementing ICD in a country



















Implementation in the US (Mortality)

- Revision of automated coding systems and decision tables
- Retraining of nosologists and medical coders
- Revision of computer edits and database specifications to accommodate new format
- Revision of tabulation lists and table programming
- Comparability study (bridge coding)
- Development of educational and promotional materials

When will the US implement ICD-11 for Mortality?

- ICD-10 took 7 years to implement from the publication of the tabular list
- Assuming:
 - Sufficient resources in terms of personnel and for changes to IT systems (database and automated coding)
 - International collaboration on revision of decision tables
- Minimum 5 years
- No sooner than 2023

ICD-11 Implementation Considerations/Challenges (Morbidity)

- WHO Licensing implications
 - Operational mechanisms regarding copyright restrictions have not been spelled out
 - How will "for US government purposes" defined? 1990 NCVHS Report stated that in the US, "government use" is not a single definition......
 - Impact that copyright on ICD-11 would have on cost and use in the US
 - Vendor implications
- WHO intention to limit development of national modifications
 - Specific limitations have not been spelled out
- Revisions to existing HIPAA standards to accommodate ICD-11 including:
 - Changes in structure and conventions
 - Changes to X12 (for example change to 5010 from 4010)
 - Post coordination
 - Clustering

ICD-10-CM Implementation Timeline



- Evaluation of ICD-10 for U.S. purposes (1994 1997)
 - Summary document available at http://www.ncvhs.hhs.gov/031105a1.htm
- NCVHS Hearings (1997-2003)
 - Summary document available at http://www.ncvhs.hhs.gov/031105a2.htm
- NPRM (2008)
- Final Rule (2009)
- NPRM (2012)
- Final Rule (2012)
- Interim Final Rule (2014)

ICD-10-CM Implementation Timeline and ICD-11 Implications for Morbidity

- Evaluation of ICD-11 for U.S. purposes (2019? 2020? 2022?)
- NCVHS Hearings (?)
- NPRM (?)
- Final Rule (?)
- NPRM (?)
- Final Rule (?)
- Interim Final Rule (?)



Thank You

Donna Pickett, MPH, RHIA

dfp4@cdc.gov

Robert N. Anderson, PhD

rca7@cdc.gov

For more information please contact Centers for Disease Control and Prevention

3311 Toledo Road, MD 20782

Telephone: 1-301-458-4434 or 1-301-458-4073

Web: http://www.cdc.gov/nchs/icd/icd10cm.htm