Update on ICD-11: The WHO Launch and Implications for U.S. Implementation

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ICD-10 Coordination and Maintenance Committee
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## ICD Revision History (Mortality and Morbidity)

<table>
<thead>
<tr>
<th>ICD Revision No.</th>
<th>Year of Conference When Adopted</th>
<th>Year in Use in the U.S. Mortality</th>
<th>ICD, Clinical Modification Morbidity</th>
<th>Year in Use in the U.S.</th>
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<tr>
<td>First</td>
<td>1900</td>
<td>1900-1909</td>
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<td>Second</td>
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<td>Seventh</td>
<td>1955</td>
<td>1958-1967</td>
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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.)
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 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
Need for an 11\textsuperscript{th} 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)
- Hundreds of scientists / clinicians have contributed
- More than 90 countries have been involved in production, reviews, testing or commenting

More than 10000 proposals received

All processed* (2 pending feedback)

*All proposals received by the deadline of 31 December 2017, plus additional proposals received after the deadline as time and urgency permitted.
ICD Revision: Web of Topic Advisory Groups (TAGs) and Working Groups (WG)

30 Topic Advisory Groups and Working Groups
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 (optional 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)

• **Phase 3**: from now until May 2019: preparations for implementation version

• **Phase 4**: thereafter: Maintenance
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
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
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 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 ICD-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

• **Print version** – 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

- Translation tools
- Reference Guide (formerly “Volume 2”)
- URIs for detailed recording (e.g. rare diseases)
- Available in many formats: online, files, web services
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 (earliest implementation date for mortality)
International Classification of Diseases
Eleventh Revision
Health information in the 21st century

allocating 70% of the world's health expenditures
110 countries report causes of death, 60% world population
use also in primary care, traditional medicine, clinical recording, digital health
scientifically up-to-date, terms can be added, easy coding, software integration, multilingual

ICD-11 Release Event and Seminar
Monday 18 June 12:00-14:00
Salle D

11 Years of work, 270 institutions, 96 countries, 11000 proposals
ICD-11 code is now stable, preparations for implementation can start
ICD-11 version for implementation June 2018

Address by Dr Tedros Ghebreyesus, Director General
Opening by Dr Soumya Swaminathan, Deputy Director General
Message by Dr Lubna Alansari, Assistant Director General HMM

Presenters include:
Dr Hiroaki Suzuki
Use Freyberg, Open Hospital Association
Dr Christopher G. Chute
Emeritus Distinguished Professor of Health Informatics
Pulmonary Diseases, Public Health, and Primary Care
Chief Research Informatics Officer, Johns Hopkins Medicine
Assistant Director, National Library of Medicine, National Institutes of Health
Dr Shashank Savani
Director, NHI - Navigational and Subclass 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
When will the US implement ICD-11 for 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? (2)

• 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
When will the US implement ICD-11 for Morbidity?

Considerations/Challenges

• WHO Licensing Implications
  - Operational mechanisms regarding copyright restrictions have not been spelled out
    - Possible vendor, systems and stakeholder implications
  - How will “for US government purposes” be defined? 1990 NCVHS Report stated that in the US, “government use” is not a single definition......

• WHO intention to limit development of national modifications
  - Specific limitations have not been spelled out
  - Will US clinical modification be needed or permitted?

• Revisions to existing HIPAA standards to accommodate ICD-11 including:
  - Changes in ICD-11 structure and conventions
  - Changes to X12 (e.g., change to 5010 from 4010)
  - Post coordination and Clustering
ICD-11 Coding scheme

- The chapter numbering:
  - now Arabic numbers
  - not Roman numerals
- The coding scheme for categories:
  - now minimum 4 characters
  - 2 levels of subcategories
- Coding scheme
  - always has a letter in the second position to distinguish from the codes of ICD-10.
  - No l,l (L,i); 0,O (Zero, o)
- First character of the code always relates to the chapter number.
  - 1-Z
ICD-11 Coding Scheme

• 1.2.4.1 Coding scheme
  • The coding scheme always has a letter in the second position to differentiate from the codes of ICD–10.
  • In ICD–11, the first character of the code always relates to the chapter number. It may be a number or a letter. The code range of a single chapter always has the same character in the first position.
  • In order to describe a causal relationship between conditions in a code title the preferred term is ‘due to’.
  • In order to indicate the concurrence of two conditions in a code title the preferred term is ‘associated with’.
  • The codes of the ICD–11 are alphanumeric and cover the range from 1A00.00 to ZZ9Z.ZZ. Codes starting with ‘X’ indicate an extension code (see Extension codes). The inclusion of a forced number at the 3rd character position prevents spelling ‘undesirable words’. The letters ‘O’ and ‘I’ are omitted to prevent confusion with the numbers ‘0’ and ‘1’. Chapters are indicated by the first character. For example, 1A00 is a code in Chapter 1, and BA00 is a code in Chapter 11.
ICD-11: Extensions

- Diagnosis timing indicator
- Severity scale value
- Dimensions of injury
- Topology Scale Value
- Specific Anatomic Detail
- Capacity or context
- Dimensions of external causes
- Histopathology
- Consciousness
- Substances
- Code usage
- Temporality
- Etiology
1.2.4.2 Extension codes

ICD–11 allows for adding specific detail to coded entities using the following mechanisms:

- The extension codes comprised of groups of codes e.g. anatomy, agent, histopathology and other aspects that may be used to add detail to a stem code. Extension codes are not to be used alone but must be added to a stem code. Not all extension codes can be used with every stem code.

- ‘Code also’ instructions provide additional aetiopathological information which is mandatory to code in conjunction with certain categories, because that additional information is relevant for primary tabulation. The ‘code also’ instruction marks the categories that must be used in conjunction with the indicated condition. In some instances, they may be a reason for treatment in their own right, where aetiology is unknown.

- ICD–11 has an explicit way of marking codes that are postcoordinated to describe one condition, called cluster coding. This is a notable new feature in ICD-11 that creates an ability to link core diagnostic concepts (i.e. stem code concepts) when desired, and/or to add clinical concepts captured in extension codes to primary stem code concepts. Either way, it should be emphasized that the clustering ability inherent to ICD-11 is one of the significant changes relative to ICD-10.
ICD-11 Cluster Coding

• Cluster coding refers to a convention used (either forward slash (/) or ampersand (&)) to show more than one code used together (e.g. stem code/stem code(s)&extension code(s)) to describe a documented clinical concept.

Example: Diagnosis: Duodenal ulcer with acute haemorrhage, Cluster: DA63/ME24.90&XA9780; Condition - DA63 Duodenal ulcer; Specific anatomy (use additional code, if desired) - XA9780 Duodenum; Has manifestation (use additional code, if desired) - ME24.90 Acute gastrointestinal bleeding, not elsewhere classified
ICD-10-CM Implementation Timeline


- ICD-10-CM pilot
- ICD-10-CM cost study

NPRM (2008)
- Final Rule (2009)
- Final Rule (2012)
- Interim Final Rule (2014)
- Implementation (Oct. 1, 2015)
ICD-10-CM Implementation Timeline and ICD-11 Implications for Morbidity

• NCVHS Hearings (?)
• NPRM (?)
• Final Rule (?)
• NPRM (?)
• Final Rule (?)
• Interim Final Rule (?)
Thank You

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For more information please contact Centers for Disease Control and Prevention

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