

# WHO ICD-10 and ICD-10-CM

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# Overview

- Review purpose and use of ICD
  - Discuss ICD-10 and ICD-10-CM
- Describe NCVHS recommendation for implementation of ICD-10-CM
- Describe updating process for ICD-10
- Discuss how rare diseases are handled in ICD-10 and ICD-10-CM

# International Classification of Diseases (ICD)

- Originated as a mortality classification
- Now used for both mortality and morbidity
- As a statistical classification, has mutually exclusive categories
  - In contrast with terminologies that have multiple hierarchies
  - If a concept can fit in more than one place, the ICD generally uses an excludes note

# ICD-10 Major Changes

ICD-10 (International Statistical Classification of Diseases and Related Health Problems, Tenth Revision) represents the broadest scope of any ICD revision to date. Changes include:

- Alphanumeric codes (A00-Z99)
- Restructuring certain chapters/ categories
- Addition of new features
- Expansion of detail (2,033 categories; 855 more than ICD-9)

# National Center for Health Statistics and Clinical Modifications of ICD, ICD-9-CM and ICD-10-CM

- Responsible for clinical modifications of the ICD in the U.S.: updating ICD-9-CM, and creation of a clinical modification of ICD-10, that is ICD-10-CM adds clinical detail and new medical knowledge
  - ICD-9-CM is now used for statistical reporting, research, billing, and other administrative uses
- NCHS houses the North American Collaborating Center for the World Health Organization Family of International Classifications

# ICD-10-CM Development

- Prototype by Technical Advisory Panel
- Multiple rounds of enhancements based on public comments and pilot testing
- Consultation with
  - Physician groups
    - Dermatology, Neurology, Obstetrics & Gynecology, Orthopedics, Pediatrics, Psychiatry, Urology
  - Professional organizations
    - ADA, AHA, AHIMA, ANA, NACHRI
  - Other users of ICD-9-CM
    - Federal agencies, Workers Comp, epidemiologists, researchers



# Advantages of Moving to ICD-10-CM

- Update clinical language, and add detail
  - Particularly helpful for rare diseases
- Capture data on factors other than disease affecting health
- Comparability with State and National mortality data
- Improve data for epidemiology and decision-support
  - Patient Safety
  - Ambulatory/managed care encounters
  - Outcomes research
  - Surveillance & prevention activities
- Increase sensitivity for refining applications such as grouping and reimbursement methodologies
- Harmonization with other classifications

# National Committee on Vital and Health Statistics (NCVHS)

Public Advisory Body to the Secretary of Health and Human Services  
**Recommendations on ICD-10-CM and ICD-10-PCS,**  
November 2003

Conclude it is in US' best interest to adopt  
ICD-10-CM and -PCS to replace ICD-9-CM

Two year implementation period after final rule

NPRM to invite comments on how to:

- Minimize cost
- Maximize benefits
- Mitigate unintended consequences
- ensure smooth migration
- consider timeframes



# WHO ICD-10 Updating Process

- The Update & Revision Committee (URC) was established to manage the ICD-10 updating process
  - Recommended changes come from WHO Collaborating Centres for the Family of International Classifications, and from the Mortality Reference Group
- Minor updates such as corrections or clarifications are made annually
- Major updates such as new codes or new terms are made every three years

# Rare Diseases in ICD-10

- Many rare diseases have specific codes in ICD-10, many of them in the metabolic disorders section (E70-E90).
- Not all rare diseases can have specific codes. As more are discovered, new rare diseases are not even all indexed.
- Rare diseases at least should be indexed, via the update process for ICD-10
- Examples of specific codes in ICD-10:
  - E70.0 Classical phenylketonuria
  - E71.0 Maple-syrup-urine disease
  - G60.1 Refsum's disease

# Rare Diseases in ICD-10-CM

- ICD-10-CM has more space to add diseases, and thus more room for rare diseases.
- Specific codes have been added for many rare diseases in ICD-10-CM.
  - Many of these are in the metabolic disorders section (E70-E90).
- Despite this, it will still not be possible to create specific codes for all rare diseases in ICD-10-CM.
- Addition of codes has some consideration of clinical utility for codes, and in some ways is an art, as well as a science.
- Some disorders are still identified with “Other disease” codes.

# Rare Diseases in ICD-10-CM

- Input and Consultation with Professional Organizations on certain rare diseases included:
  - American Academy of Neurology
  - American Academy of Pediatrics
  - American College of Medical Genetics
- Many rare diseases have been indexed.
- Sometimes codes are added for very rare disorders, depending on potential clinical utility of the code, and structure of the ICD.

# ICD-10-CM Example

## E74.0 Glycogen storage disease

- E74.00 Glycogen storage disease, unspecified
- E74.01 Von Gierke's disease  
Type I glycogen storage disease
- E74.02 Pompe's disease  
Cardiac glycogenosis  
Type II glycogen storage disease
- E74.03 Cori's disease  
Forbes' disease  
Type III glycogen storage disease
- E74.04 McArdle's disease  
Type V glycogen storage disease
- E74.09 Other glycogen storage disease  
Andersen's disease  
Hers' disease  
Tauri's disease  
Glycogen storage disease, types 0, IV, VI-XI  
Liver phosphorylase deficiency  
Muscle phosphofructokinase deficiency

# Summary

- Many rare diseases have had specific codes added in ICD-10. Even more were added in ICD-10-CM.
- ICD-10 and ICD-10-CM are classifications, and will not have a specific code for each rare disease.
- Expert opinion has been obtained on addition of new codes for particular rare diseases. Continued dialog is welcomed.



# References

- ICD-10
  - <http://www.who.int/classifications/icd/en/>
- ICD-10-CM and ICD-9-CM
  - <http://www.cdc.gov/nchs/icd9.htm>
- NCVHS
  - <http://www.ncvhs.hhs.gov/>