ICD Revision Process: towards ICD -11

Dr. T. B. Üstün
WHO

Cologne – Helsinki – Reykjavik
Planning for Revision

- Continuous life cycle
  - Knowledge Management
  - strategic vision - purpose - users - policy
  - recognition of need & perspective: how & when
  - Software release methodology
- Beyond Prejudgement: conservatism vs novelty
  - undermining the ICD-10, ICF ?
  - New = better ?; Old = better ?
  - Marketing strategy
  - Credibility management
  - backward compatibility
  - real response to need
- systematic evaluation
  - impact, process
- serious planning for revision
  - needs, resources, timeplan, customers, partners

Key Drivers

- Mandated by WHA and EB
- Respond to consumer-needs
  - Clinicians, Administration, Patients, families; Data-users
- Keep up with new scientific knowledge
  - New Diseases, Treatments, Terminology,…
  - Corrections: pruning and grafting, deletions
  - Change in rules, guidelines, conventions,…
- Compatibility within the WHO-FIC members
  - ICF, ICHI, ICEDI, ICD-O,…
- Creation of an improved network and dissemination
- Better implementation within Health Information Systems
  - Electronic Health Record, Clinical Terminologies, Mortality Database

ICD Revisions
UP-dating vs Re.vision

- **UPDATING**: 
  - Build on ICD-10 
  - Corrections, quick fixes of problems 
  - Insertion of further detail 
  - New terms 
  - Harmonization 
  - Cumulative updates 

- **REVISION**: 
  - More than Update: 
    - Difficult to update conditions 
      - Mitochondrial diseases, Cystic Fibrosis, Diabetes Mellitus 
    - Structural changes 
    - New concepts ...

“Revision” of ICD

- Design requirements for compatibility within family 
  - relatively major changes in chapters, blocks 
  - re-coding / elimination of whole sections 
- Design requirements for implementation tools 
- Incorporation of new elements of classification 
  - genetic information? 
  - Linkage to interventions - procedures 
  - joint use of ICD-ICF & ICHI...
- Visioning ICD-11 in the emerging e-health applications

DESIDERATA for ICD-11

- Compatibility with National Classification schemes 
  - Bottom-up perspective 
- Multiple coding schemes for: 
  - Mortality 
  - Morbidity 
  - Epidemiology 
  - Administration 
- Translatability 
  - ? Local language relevance 
- User-friendliness 
- Application tools 
- Development in a technical database with metadata

Other Products

- Electronic Version 
- CD/DVD 
- WEB Version 
- Terminologies 
- Translations 
- Classification Maintenance System 
- ClaML / XML 
- Schemas 
- Language Versions

Web Version
Technical Aspects

- Development in a database environment
  - XML – classification mark-up language
  - Meta data
- Definitions, Diagnostic features
- Inclusion and exclusion
- Extension and Collapsing of codes
- Index
- Mapping
- Specialty extensions – Oncology, Mental Health.
- Hierarchy of coding rules
  - Main cause, Multiple cause, …
- Links with the Family Members
- Data Quality Tools

Issues raised in this meeting for ICD Revision

- MORTALITY: Short Mortality List(s)
- MORBIDITY: Compilation of micro-data
- Dagger & asterisk
- Evidence based revision process
  - Scientific literature on taxonomy
  - Administration requirement for better management
- updates: what has/ has not been addressed ?
- User demand and response to need
  - change in national classifications
    - ICD - XM
    - DSM – V
    - Other classification systems: Chinese, Cuban, Latin American…

Basic Questions

- Mortality vs. Morbidity

Key Inputs

- Evaluation of ICD-10 Implementation Process
  - ICD-10 Update Process
Work Streams

1. Epidemiological Stream
   - Surveys
   - Validation Studies
   - Add-on protocols for existing studies
   - Meta analyses

2. Clinical Stream
   - Clinical utility – linkage to patient reports
   - Treatment Response
   - Phenotypes: gene to behaviour spec

3. Knowledge Management & Sharing
   - WEB based tools for open access and commentary on
     Disease Categories, Definitions and Criteria
   - Structured Discussion Forums
   - Evidence based systematic reviews & Knowledge Base
   - ICD Journal on-line
   - Translation tools

Involvement Strategy

- International:
  - Multiple countries
  - Multiple languages
  - Multiple health care systems

- Multiple Parties & Professionals
  - Different clinical specialties, nursing & midwifery; other professionals

- Different health care aspects:
  - primary care
  - home care
  - rehabilitation
  - long term care

- Consumers from different sectors

Structure for Revision Process

- Central revision team
  - Coordination
  - Editing
  - IT

- Network of Centers
- WHO Regional Offices and Technical Programs
- International Expert Groups
- Annual Revision Meetings
- Partners
- Specialty Reference Groups

➢ Permanent Knowledge Portal
Knowledge Portal
Web of ICD Revision

**WEB based tools for open access and commentary**

- Evidence based systematic reviews
  - Clinical Use
  - Epidemiology, demography and public health
- Knowledge Sharing
  - All ICD Chapters
    - Disease Definitions and Criteria
    - Comment threads
    - Structured Discussion Forums
  - Field Trials: Global Practice Networks to test the proposed codes, definitions...
  - Classifications On-line Journal

➤ **Personalized selections in an interconnected electronic environment**
  - Actionable information – alerting, planning, query, reporting & analysis
  - Collaboration (Executive, Knowledge worker, User)

ICD Revision Process

- Drafting Rules
  - Taxonomic Guidelines
  - Definition, Diagnosis and Indexing / mapping guidelines
- Drafting Overall Structure
- Drafting Individual Chapters
- Overseeing the TOTAL ICD
  - ALPHA Draft – structured comments
  - BETA Draft – field testing
- Final Draft
  ➤ WHA Approval

Revision Business

- Environment/Context
  - Barriers & Facilitators
- Agents
  - WHO FIC Network, Partners, Competitors
- **Product**
  - ICD-11, supporting materials
- **Market Analysis**
  - ICD-10 countries
  - New users
- **Operational Plan & Business Model**
- **Financial Statements**
- **Risks**
- **Presentation- Communication - Approval**

Development Strategy

- **Marketing analysis**
  - Consumer needs
  - Stakeholder involvement
- **Communication Strategy**
  - Invitation to Member States
- **Resource Mobilization**
  - Human resources
  - Financial resources
  - IT resources
- **User involvement**
  - Technical experts, clinicians
  - Administrators
  - Consumers

Packaging the Final Product

- **Update & Compatibility Package:**
  - Use in Mortality Database (time series / bridge coding…)
  - Use in other national applications
- **Training Materials**
- **Implementation Materials**
  - Coding Tool
  - Linkage to IT Systems - e-Health Record (terminologies)
- **Trainers’ Network**
- **Data Quality Tools**
Working Principles

• Shared leadership
  – Network recognition – responsibility - accountability
• Network consensus building
  – Differences surfaced
  – Multi-party agreement
• Process / task oriented
• Empowerment of interested parties / accountability / transparency

Field Trials

e-Questionnaires within a Global Practice Network

• Relevance
  – Appropriate coding – fit for purpose
  – Scientific accuracy
  – Guidance for case-management
• Coverage
  – Completeness/missing elements
• Utility
  – Feasibility, benefits
  – Explanatory power: need, costs, utilization
  – User acceptance: barriers
• Trends
  – Statistical time series
  – Bridge coding studies
  – Projections
• Translations
• Computer Applications
  – Links with other IT tools
  – Mapping with Terminologies

Tentative Timeline

• ICD-11 by …
  – 2004/5: International Consultations for blueprint
  – 2005 : Start of multiple streams of workplan
  – 2006 : Alpha version
  – 2007 : Commentaries and consultations
  – 2008 : Beta version & Field Version
  – 2009 : Field trials
  – 2010 : Final version for public viewing
  – 2011 : WHA Approval
  – 2013+: implementation