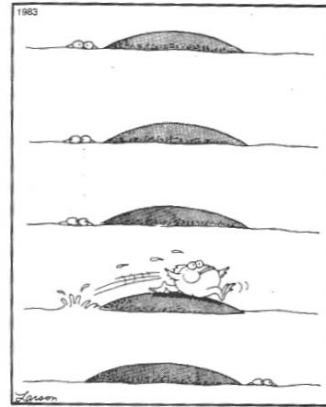


## ICD Revision Process: towards ICD -11

Dr. T. B. Üstün  
WHO



Another great moment in evolution

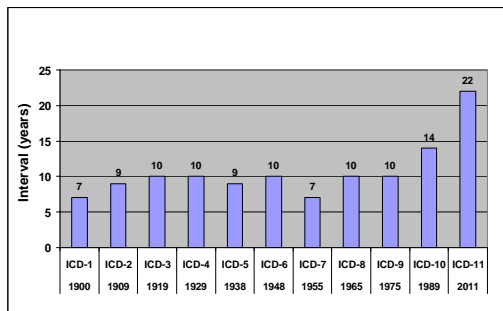
### Cologne – Helsinki – Reykjavik Planning for Revision

- **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, ICECI, 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
    - ICD-10 Second Edition (2004)
- **REVISION**
  - More than Update:
    - Difficult to update conditions
      - Mitochondrial diseases, Cystic Fibrosis, Diabetes Mellitus
    - Structural changes
    - New concepts ...

ICD-10  
Update



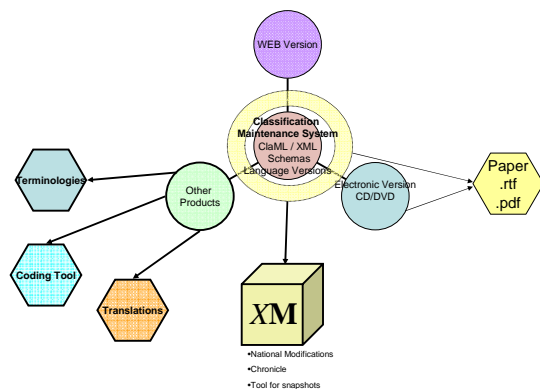
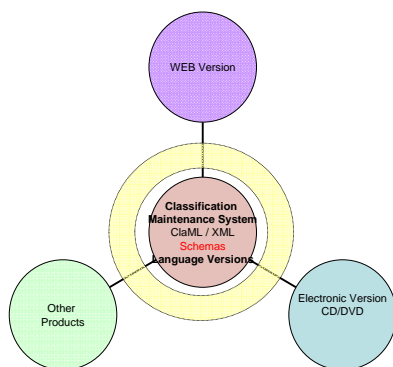
ICD-11

## “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



## 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

If you are **NOT DEAD**, we are **NOT INTERESTED**



"Fill out this tag and attach it to your big toe."

## Basic Questions

- Mortality vs. Morbidity
- Statistical Reporting
  - vs. Administration
  - vs. Epidemiology & Services Research
  - vs. Clinical Decision-making
- Others:
  - Continuity vs. breaks
  - Distinction of **Disease** categories
    - and other entities: Reasons for encounter

## Key Inputs

- **Evaluation of ICD-10 Implementation Process**
  - ICD-10 Update Process



## Key Inputs

- **Evaluation of ICD-10 Implementation Process**
  - ICD-10 Update Process
- **ICD-10 XM**
- **Family Congruence**
  - ICF
  - ICD Derived classifications: ICD-O 3 and others; ICD-XM
  - ICD Related classifications: ICECI, ICPC
  - ICHI (implications)
- **IT & Standards requirements**
  - Terminology Links – mappings
  - ISO standards + HL7
- **Structural amendments**
  - XVIII, XX, XXI – Distinction: Diseases; Signs, symptoms; interventions

## Work Streams

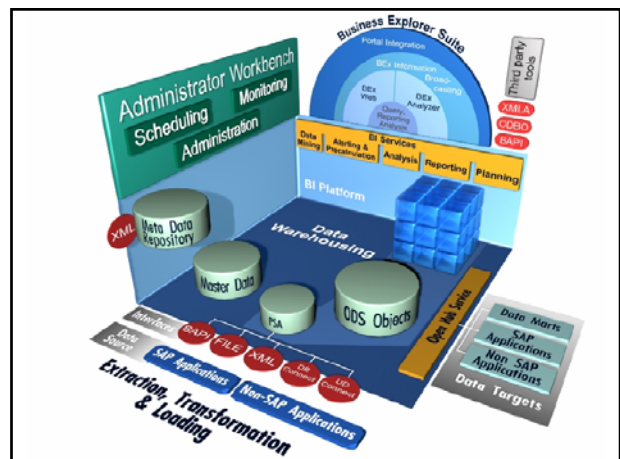
1. **Epidemiological Stream**
  - Surveys
  - Validation Studies
  - Add-on protocols for existing studies
  - Meta analyses
2. **Clinical Stream**
  - Clinical utility – linkage to patient reports
  - Treatment Response
  - Phenotypes: gene to behaviour specs
3. **Knowledge Management & Sharing**
  - 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



*"Ah, Mr. Bromley. Nice to put a face on a disease."*

## 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**
  - Comprehensiveness, 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**

