Summary of progress
Neurology Advisory Group
Clinical utility

Neurosciences Topic Advisory Group
1. Donna Bergen, USA.
2. Pierre Bill, South Africa.
3. Mandaville Gourie-Devi, India.
5. Mohamad Mikati, Lebanon.
6. Hidehiro Mizusawa, Japan
7. Raad Shakir, United Kingdom (Chair)

Neurological NGOs:
8. Murat Emre, Turkey.
10. Marc Patterson, USA
11. Jes Olesen, Denmark
12. Ettore Beghi, Italy
13. Andreas Monsch, Switzerland.
14. Kapil D Sethi, USA.
15. Alan J. Thompson, Director, UK.
16. Marc Levivier, Switzerland.

WHO SECRETARIATE 2009.
19. Tarun Dua,
20. Robert Jakob,
21. Geoffrey Reed,
22. Benedetto Saraceno.,
23. Shekhar Saxena,
24. Bedirhan Ustun,
25. Rosemary Westermeyer,
Utility for whom?

- Experts in AMCs with state of the art technology (imaging, genetics)
- Global neurologists
- Primary care physicians in high-income, high-tech countries
- Non-specialist (non-physician) providers in community-based primary care

Advanced Market commitments
International Classification of Diseases – 11th Revision

USES OF ICD

• Used by countries/healthcare providers/Research institutions
• Capturing Mortality and Morbidity (Worldwide/countries/regions)
• Determining allocation of healthcare resources
• Scientific research
• Epidemiological studies
• Coding and financial implications to healthcare providers

Overarching ICD-11 revision goals

• To produce a multi-purpose, coherent, international and multilingual classification
  o Mortality, morbidity, primary care, clinical care, research, public health...
  o Consistency and interoperability to enhance scientific comparability and communication across different uses, respectively

• To ensure that ICD-11 will seamlessly function in an electronic health records environment.
  o Link ICD logically to underpinning terminologies and ontologies (e.g. SNOMED, GO, ...)
  o ICD Categories “defined” by “logical operational rules” on their associations and details
“The ICD-11 Difference”

- Digital curation
  - Ontology based
- Enhanced discussion & peer review
  - TAGs serve as the editorial group
  - Electronic copy → print version
- Work in multiple languages
- Planned field tests
  - Based on Use Cases
- Internet-based permanent platform
  - All year round
  - Open to all people in a structured way
  - Content experts focus

Timeline

2008
- Project planning and budgeting document released
- Core Classifications team set up as main coordinating body for ICD-11

2009
- Neurology advisory group compiled and met in Geneva for 1st annual meeting

2010
- Two advisory group meetings, 16 working groups established
- First revision proposals from working groups

2011 & 2012
- Content models and linear structures developed
- Cross linking with other chapters
- Fund raising for field trials
- ICD-11 made public for online viewing
  (http://apps.who.int/classifications/icd11/browse/f/en)

Present
- Electronic field trials planning
- Final tweaks to linear structures
- Content models still under development but will soon be finalised
International Classification of Diseases – 11th Revision

BACKGROUND:

ICD-10

• Has been in use for approximately 20 years
• Available in 42 languages including the 6 official languages of WHO
  (Arabic, Chinese, English, French, Russian and Spanish)

International Classification of Diseases

ICD-10: The problems

Constraints on the total number of blocks per chapter

Lack of an accurate and intuitive organization w.r.t classification of neurological disease

*In ICD-10:

Episodic and paroxysmal disorders (1 block)
  • Epilepsy
  • Headache
  • Cerebrovascular disease

*In ICD-11:

Epilepsy, headache and cerebrovascular disease all have separate blocks
International Classification of Diseases

ICD-10: Other disorders of the nervous section

Large block containing a diverse group of disorders:

- Disorders of CSF pressure and flow
- Disorders of the autonomic nervous system
- Disorders of the spinal cord
- Disorders of consciousness

Each has a separate block in ICD-11

Structure of ICD-10 Chapter 6: Diseases of the nervous system

- G00-G09 Inflammatory diseases of the central nervous system
- G10-G14 Systemic atrophies primarily affecting the central nervous system
- G20-G26 Extrapyramidal and movement disorders
- G30-G32 Other degenerative diseases of the nervous system
- G35-G37 Demyelinating diseases of the central nervous system
- G40-G47 Episodic and paroxysmal disorders
- G50-G59 Nerve, nerve root and plexus disorders
- G60-G64 Polyneuropathies and other disorders of the peripheral nervous system
- G70-G73 Diseases of myoneural junction and muscle
- G80-G83 Cerebral palsy and other paralytic syndromes
- G90-G99 Other disorders of the nervous system
# Structure of ICD-11 Chapter 6: Diseases of the nervous system

<table>
<thead>
<tr>
<th>A.</th>
<th>Infections of the nervous system</th>
<th>O.</th>
<th>Nutritional and toxic disorders of the nervous system</th>
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<td>Prion diseases</td>
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<td>H.</td>
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<td>Disorders of consciousness</td>
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<td>J.</td>
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<td>Cerebral palsy</td>
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<td>M.</td>
<td>Structural developmental anomalies of the nervous system</td>
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<td>N.</td>
<td>Syndromes with central nervous system anomalies as a major</td>
<td></td>
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</tr>
</tbody>
</table>

## International Classification of Diseases – 11th Revision

### NEW BLOCKS IN ICD-11

- Epilepsy
- Headache
- Cerebrovascular disease
- Disorders of CSF pressure and flow
- Disorders of the autonomic nervous system
- Disorders of the spinal cord
- Disorders of consciousness
- Prion diseases
- Paraneoplastic and autoimmune disorders of the nervous system
- Nutritional and toxic disorders of the nervous system
- Functional disorders of the nervous system
International Classification of Diseases – 11th Revision

AREAS OF DEBATE:

1) Classification based on anatomy/pathology/genetics/clinical features?

2) Proliferation of genes and autoantibodies
   - How detailed should the classification be?

3) Overlap, repetition and redundancy

Neurology TAG’s key responsibilities

- To identify key areas for review (e.g., areas of controversy or rapid change; specific utility questions)
- To match specific methods to questions, decide on strategies, marshal resources for necessary work
- To identify broad and obvious structural changes that should be considered due to advances in scientific knowledge or changes in practice
- To evaluate alternative or supplementary classifications in specific areas (e.g., developed by professional organizations) in terms of their objectives, structure, use, and implications for revision of ICD Chapter VI
- To answer to specific uses and needs of particular users of ICD Chapter VI
- To generate discussion on entities (diseases of the nervous system) outside Chapter VI
Neurology TAG Working Groups (WG)

- Cerebrovascular diseases
- Demyelinating disorders
- Epilepsy and seizures
- Headache and related disorders
- Infections of the nervous system
- Movement Disorders and neurodegenerative disorders
- Neuromuscular junction and muscle disorders
- Nutritional and toxic disorders of the nervous system
- Root, plexus and peripheral nerve diseases
- Other disorders of the nervous system, including disorders of consciousness, autonomic nervous system, others
- Disorders first recognized in infancy, childhood and adolescence
- Neoplasms of the nervous system
- Traumatic injuries of the nervous system
- Neurocognitive disorders (joint with Mental Health TAG)
- Signs and symptoms
- Disorders first recognized in infancy, childhood and adolescence

Prerequisite Activities
- Linear structure
- Content model
- Field studies

“Evidence-based evaluation”
- Literature review
- Expert consensus
- Evaluation of current ICD applications
Update on Linear Structure

- Phases:
  - Creation and Revision by Working Groups
  - Comments from WHO and Topic Advisory Group (TAG)
  - Final version from TAG
  - Entry into ICAT (online portal)
- Linear structure received from most groups
- Finalized:
  - Cerebrovascular diseases
  - Epilepsy and seizures
  - Headache and related disorders
  - Movement Disorders and neurodegenerative disorders
  - Neuromuscular junction and muscle disorders
  - Motor neuron disease and related disorders
  - Root, plexus and peripheral nerve diseases
  - Prion disorders (located within the section “other disorders of the nervous system”)

Content Models

- Short definition, signs & symptoms, investigative findings +/- synonyms
- Not including diagnostic criteria, as is seen in the mental health chapter
- Definitions are concise (<100 words) and are meant to be diagnostically useful, more than just coding information
- Asymmetry inherent: common and uncommon, complex and easy-to-diagnose diseases will both get <100 words in definition
- Focusing first up to four digit level
Cross Specialities Issues

- Major:
  - Stroke resolved
  - Trauma of the nervous system ongoing
  - Dementia resolved
  - Infections resolved
  - Neoplasm resolved
- Minor:
  - Ophthalmology
  - Paediatrics
  - Rare diseases eg Prion diseases resolved

Electronic field trials (2013-2014)

- Establishment of the **Global Neurology Network** (GNN) for general doctors, neurologists and neurology health care workers

  [Link](http://kuclas.qualtrics.com/SE/?SID=SV_2tx46PqQkVAyeQB)

- GNN will be sent online surveys: ICD-10 Vs. ICD-11 to code carefully designed case vignettes

- Inter-rater reliability and supplementary questions w.r.t the usability and clinical validity of the ICD-11
Primary Care Version

• Core version, essentials
• Classification and education
• Longer more informative
• Aetiology, diagnosis, management
• Choosing 50 disorders