Questionnaire regarding nomenclatures for concepts related to health technologies

1. Name of the "nomenclature"


2. Name and legal status (Inc, Plc, Ltd, …) of the organization that manages the nomenclature system

| World Health Organization (International Organization) |

3. The organization that manages the nomenclature

a. Please describe the governance and management of the body responsible for maintaining the nomenclature.

| WHO Classifications, Terminology and Standards (CTS) Unit is responsible for development, maintenance and implementation of ICD. The work is a constitutional mandate of the WHO. The governance is through WHO. The technical maintenance is supported by WHO Member States, and a special network for the Family of International Classifications (WHO-FIC) which comprises the WHO Collaborating Centres for the Family of International Classifications, WHO Regional Offices, national classification centres, NGOs, academic and research centers. |

b. How is broad stakeholder representation ensured?

| The WHO FIC Network represents a wide range of stakeholders including government agencies, service providers, professional organizations, NGOs, academic and research centers. |

c. How is broad geographical representation ensured in governing bodies?

| The geographic representation is for 193 WHO Member States. Structure of WHO FIC Network covers all 6 WHO Regions – 20 centers and some 20 additional associated entities. |
4. **Background to the creation of the nomenclature**

**Please outline the scope of the mandate to engage in classification and naming**

WHO is the custodian of the ICD and it is a WHO Constitutional Mandate (Article 2). 1967 International Nomenclature Regulations forms the basis of an international treaty that all WHO Member States use ICD to report health statistics and other international comparisons.

5. **What is the intended purpose/use of the system?**

Systematic recording, analysis, interpretation and comparison of mortality and morbidity data at population and individual level. In various sections there are standard definitions and diagnostic guidelines to serve as diagnostic standards. The ICD is used to translate diagnoses of diseases and other health problems from words into an alphanumeric code, which permits easy storage, retrieval and analysis of the data.

6. **Mandatory use of the nomenclature**

   a. **Has any country or organization made it mandatory to use the nomenclature for specific purposes?**

The International Nomenclature Regulations call for a mandatory use by all WHO Member States. Use of ICD varies by country. Purposes include: cause of death certification; mortality & morbidity statistics; diagnostic standard for clinical care and primary care; administration, billing and reimbursement of health services.

7. **Please comprehensively describe the structure of the system. The structure and format of terms, the relations between terms, design principles for creating terms etc. Current IT implementations by the "management organization" and by users are also of interest.**

The 10 Revision of the ICD comes in three volumes (Volume 1: Main classifications with 21 chapters; Volume 2: Coding instruction and guidance; Volume 3: Alphabetical Index).

The classification is grouped by different chapters.

These chapters are extended as “Specialty Adaptations” as derived classifications in Oncology, Mental Health, Neurology, Dentistry, External Causes and Injury etc.

Some countries have taken on the existing ICD-10 base and have developed extensions on the coding systems with further details of severity, lateralization, etc. which are called National Extensions (e.g., ICD-10- CM).
8. **Are the terms used in the classification system generic i.e. non proprietary?**

- ICD codes and terms are international public goods protected under WHO copyright.
- These are sold as books from WHO Press at a nominal cost.
- The electronic use of ICD is free for governmental purposes.

9. **Maintenance of the nomenclature system**
   a. **How is the system maintained?**

- WHO in collaboration with its WHO FIC Network has established an annual ICD update cycle. Furthermore, WHO is revising the classification on a regular basis. Currently the 11th revision of ICD is oncoming and expected to be completed in 2014.

   b. **Please describe the process for creating or modifying terms in the system.**

- ICD Update process: ICD users worldwide submit update proposal on a web-based ICD Update platform. Proposals are reviewed by experts from the WHO FIC Network and subsequently implemented.

- ICD Revision process: WHO established an ICD revision structure with 20 Topic Advisory groups covering the different ICD content areas and use cases. A WIKI like international web-based Collaborative Authoring Tool (iCAT) has been created to develop ICD 11.

   c. **How is transparency ensured with regard to development and maintenance of the nomenclature?**

- Information such as a revision plan, workflows, parameters for classification development, update criteria and governance structure is shared among all collaborators and stakeholders.

- Internet platforms like iCAT and ICD update platform are open to everybody and allow to see and follow the ICD development and maintenance work.
10. Different language versions of the nomenclature
   a. How is the translation of terms and definitions managed?
      Through translation guidelines and linguistics evaluation. ICD-11 development will include translation protocols for field testing and is aiming for multilingual development in iCAT.
   
   b. What language versions exist as of February 2011?
      ICD-10 has been translated in 42 languages.
   
   c. What language versions are under translation as of February 2011?
      In light of the upcoming release of ICD-11 further translation of ICD-10 are not envisaged.

11. Endorsement of the nomenclature system
   a. Has the system been endorsed by stakeholders (healthcare professionals, Ministries of Health, industry, regulatory bodies etc.)?
      ☑ Yes    ☐ No

      Please indicate the names of the entities which have endorsed the system.
      ICD is the international data standard for reporting mortality and morbidity data. All WHO Member States world endorsed the classification in the WHA. All countries are using ICD for official statistics.

12. Implementation in IT systems, interoperability and intellectual property
   a. Please outline the intellectual property state of the nomenclature system. Please include reference to the ownership of the terms used.

      WHO holds the IP for ICD.
      WHO currently holds the copyright of ICD-10 in the six UN official languages. For ICD-11 WHO will hold copyright for all language versions.
b. Is the system available as a package for integration into user IT systems (maintenance management, adverse event reporting, procurement….)?  ☑ Yes

☐ No

c. Please specify the conditions of agreements for use in user IT systems.

Use of ICD database in electronic application is subject to WHO licensing agreements for commercial or institutional use. It is provided with a special EULA in CLAML and other formats

13. Interoperability

Please specify compatibilities ensured and mappings to other nomenclatures maintained.

Work to establish semantic interoperability and operational linkages between ICD and the following classifications & terminologies is ongoing: ICF, ICPS, ICTM, ICHI, ICPC.

ICD-10 is being mapped to SNOMED-CT. And ICD-11 is being built with special linkages to SNOMED-CT.

14. Model for sustainable financing

a. How is the system financed? I.e. user fees, member fees, subscriptions, one off payments, open source?

Currently the ICD work is funded through WHO budget. Additional funding comes from external funding.

WHO Press obtains income from book sales.
WHO Press is retaining licensing fees from commercial applications of ICD-10.

b. What is the cost of the nomenclature to specific users (governments, industry, health care providers)?

ICD is provided for free to Member State Government – for governmental use.
For commercial use, WHO Press charges a licence fee depending on the specific purpose and context.