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## **eHealth: standardized terminology**

### **Report by the Secretariat**

1. The Executive Board at its 118th session discussed the future directions of WHO's role in the development of standardized clinical terminologies with regard, in particular, to a proposed independent organization for standards development.<sup>1</sup> Over the past 40 years a comprehensive clinical terminology has been developed by the College of American Pathologists, United States of America and Connecting for Health, United Kingdom of Great Britain and Northern Ireland.<sup>2</sup> For countries adopting this standardized terminology, it was proposed to set up an independent organization to develop and maintain this clinical terminology as an international public good. Eight Member States have jointly formed an international standards development organization which will come into operation on 1 January 2007 as a not-for-profit entity, located in Denmark.<sup>3</sup>

2. In general, the Board considered that WHO should be engaged in the field of standardized clinical terminologies. WHO's expertise in international health systems and health information systems and its previous record in establishing international classifications would facilitate such an undertaking which, in turn, could enhance electronic health-information systems and activities such as global surveillance, and patient safety. WHO's involvement would ensure equal access to a standardized terminology for all Member States, but should not delay progress of international initiatives.

3. The Board reviewed several options for WHO's involvement. Two were favoured for further discussion on their technical and financial implications:

(a) in collaboration with international standards organizations (e.g. International Organization for Standardization, the European Committee for Standardization and others) WHO would play an active role in setting health information standards and rules that apply to any international health terminology, such as comprehensiveness, adequacy, multilingualism, utility, reliability, validity, interoperability and continuous quality improvement which would improve the input from health sector to the development of standardized terminologies;

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<sup>1</sup> See document EBSS-EB118/2006/REC/1, summary record of the fifth meeting.

<sup>2</sup> Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT, registered trade mark).

<sup>3</sup> Australia, Canada, Denmark, Lithuania, New Zealand, Sweden, United Kingdom of Great Britain and Northern Ireland and United States of America.

(b) WHO could collaborate with the standards development organization by, for example, representing the interests of its Member States, particularly developing countries that cannot become members in their own right of such an organization, or taking part in the harmonization board to lead mapping activities between the systematized nomenclature and WHO's classifications.

4. The Secretariat has started to examine the status of various terminology developments and their deployment in Member States. In addition, WHO has invited a number of international experts and academic research centres to collaborate in preparation of an international agenda and workplan for health terminology within a network that would share knowledge in order to create international normative tools and standards. The network would assist WHO to create an infrastructure that would support the development, application and interoperation of health terminologies. Its work would include fostering consensus on, and standardization of, representation of health knowledge, tools for development and distribution of multilingual terminology, links between terminologies and classifications, and quality assurance procedures based on empirical usability tests. It would also provide advice in practical technical tasks such as identifying terminology requirements for health information systems.

5. Discussions between the Secretariat and founding members of the fledging standards development organization led to the conclusion that WHO should not take part in the management board as a member with rights and responsibilities similar to those of the founding members. It was considered however, that an invitation for WHO to attend management meetings for the discussion of specific items was both acceptable and desirable. It was understood that WHO would participate as an observer, thus able to participate in discussions and provide technical input but not to participate in decision-making.

6. Under option (b), WHO's participation in the harmonization board could involve mapping for the International Classification of Diseases, the International Classification of Functioning, Disability and Health, and other members of the International Classifications such as classification of interventions or tumours, and classifications for drug utilization studies, in order to link clinical terminologies to classifications. It could also involve use of the systematized nomenclature in preparation of the eleventh edition of the International Classification of Diseases in order to link terminologies and classifications and ease future mapping efforts. The maps would be made widely available in order to foster interoperability within health-information systems once a quality-assured map was approved by WHO and the standards development organization.

7. WHO's experience in multilingual representation of various terminologies and taxonomies would be of value when multilingual applications of a standardized clinical terminology are created. The systematized nomenclature exists in English and other languages, including French, German and Spanish; the Secretariat has a number of translation tools that could be of use in other translations under way. A feasibility study on ways in which WHO's expertise and tools can be used to assist in the translation of quality standards could be considered as an early component of its involvement.

8. WHO could also participate in the research and development activities related to standardized terminology in support of international efforts. Potential public health benefits could be enhanced by combining data from various individual electronic health records for analysis at facility or population levels. For instance, evidence is currently compiled on electronic health-record systems to assess the extent to which the systems can provide essential data for core indicators of health systems. This knowledge aims to assist ministries of health in integrating these systems in their health information infrastructure.

9. Further, WHO could promote standardization of health care terminology, fostering both technical tools and regulatory efforts such as the WHO Nomenclature Regulations, on the basis of the following principles:

- multilingualism: to provide a truly international and multilingual framework, relevant concept-based translation and linguistic representation mechanisms need to be developed
- shared technological standards: appropriate technological tools need to be used to develop, maintain and update norms and standards in a systematic and harmonized fashion
- web-based systems for generation and distribution of data: such systems would facilitate open development, review and sharing of information
- continuous quality improvement: the continuous development, maintenance, updating and revision of clinical terminologies would be supported by a quality-assurance framework based on empirical usability tests
- measures for equitable and balanced dissemination: steps need to be taken when engaging in research and dissemination to ensure that benefits are shared in an optimal and equitable way, particularly in developing countries.

10. The following activities have been identified as priorities for the Secretariat's work in the area of standardized terminologies:

- to provide support to Member States in the development, application and management of national and international standardized terminologies compatible with WHO International Health Regulations (2005) and other reporting mechanisms, WHO Nomenclature Regulations, and the WHO family of international classifications in order to facilitate effective exchange of information among Member States and with WHO
- to facilitate development of multilingual representation of the standardized terminologies
- to participate in the harmonization board of the standards development organization, focusing on the mapping activities between the systematized nomenclature and WHO's classifications.

## **ACTION BY THE EXECUTIVE BOARD**

11. The Executive Board is invited to note the report and to provide guidance on the priorities proposed for the Secretariat's work.

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