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## **eHealth: standardized terminology**

### **Report by the Secretariat**

1. Standardization of health information is essential for its use and sharing by consumers, providers, policy-makers and others. Standardization refers to creation of accepted specifications (e.g. definitions, norms, units, rules) that establishes a common language as a basis for understanding and exchange of information between different parties. If used consistently, the standardization process enhances accuracy, efficiency, reliability and comparability of health information at local, regional, national and international levels. For example, the International Classification of Diseases was created in 1853 by the International Statistical Congress as a “uniform nomenclature of causes of death applicable to all countries” and has been used as a standard to report mortality and morbidity in Member States, yielding important information about population health over decades.
2. Beyond mortality and morbidity classifications, there is a great need for increased standardization in health information systems to bring various elements together. Progress in health sciences and information technology has resulted in an explosion of knowledge that calls for standardization to collect, store, archive, retrieve, process and analyse vast amounts of data in health care. Clinical care emerges as a priority domain because patient recording and reporting systems will benefit from a standardization process. A standardized clinical terminology is a compilation of terms used in the clinical assessment, management and care of patients, which includes agreed definitions that adequately represent the knowledge behind these terms and link with a standardized coding and classification system.
3. Use of standardized terminology will result in better and safer patient care and more efficient health services. More recently, it has been recognized that standardized information could underpin statistical reporting, decision-making, measurement of outcomes and performance, and cost analysis. It could also enhance work on population health, including disaster management and disease surveillance. For these purposes, multiple dimensions of the underlying terminology need to be properly captured and standardized.
4. In parallel, progress in eHealth applications has led to increasing use of electronic health records which also require a standardized clinical terminology. The exchange of information in eHealth applications requires both standards for information technology (e.g. technical specifications for communications between different computer systems) and content (e.g. a terminology which ensures that information exchanged between different users will be faithfully understood and reliably used). Content standards, independent of technical standards, must reflect the most advanced scientific understanding of the concepts and adhere to the best available knowledge-representation principles. Electronic documentation of patient records and representation of health information in computer applications calls for a standard data structure of clinical terminology that can be processed by machines.

5. A number of terminologies and nomenclatures for exchange of information have been created. There is a need for concerted action for developing internationally agreed criteria in order to review materials and provide standardized terminologies as reference for a unified standard. Such standardized reference terminologies need to be stored in an international repository as international public goods, preserving the legitimate copyright of the contributors, while ensuring optimum usability and affordability for all Member States.

## EXPLORATORY STEPS TAKEN

6. The Secretariat and the network of Collaborating Centres for the WHO Family of International Classifications have engaged in exploratory discussions with developers of terminologies and with the academic and industrial researchers who develop tools and methods for assessing such products. The standardized terminologies need to be linked to the international classifications in health which WHO has developed and maintained over the years. Terminologies expand the key concepts in classifications with more detailed terms. For example, signs and symptoms of an illness are represented in a clinical terminology, whereas a classification lists the diseases.

7. Under a European Union Specific Support Action, WHO entered into a partnership agreement with several research institutions which aims at guiding research leading to short and medium-term interoperability solutions. Interoperability refers to mechanisms that ensure unambiguous exchange of information between systems. Apart from technical standards, to ensure that the same meaning is preserved in this exchange standardized terminologies based on a system of concepts (i.e. ontology-based terminologies) are expected to play a key role. Without such standardization, there is a potential for error in all communications, which may compromise the efficiency of health-care systems and care of citizens.

8. An international systematized nomenclature of medicine-clinical terms has been developed that contains some 400 000 clinical terms.<sup>1</sup> The developers of this nomenclature have jointly proposed that an independent standard development organization should be set up to develop and maintain this clinical terminology as an international public good.<sup>2</sup>

9. Substantial resources have been invested to compile this and other current terminologies, which still need to be developed further and maintained. The task for the international community to turn national contributions into truly international public goods is immense, and best use should be made of existing solutions. Since December 2005, a number of Member States which were invited to join this initiative have expressed the view that WHO could become directly involved in such an undertaking because the development of global norms and standards for health information systems corresponds to WHO's mandate. Further, WHO's international expertise in health systems and health information systems, and in establishing international classifications would facilitate both this undertaking and the development of the reference terminology in different languages.

10. Regarding WHO's involvement in the international standardized terminologies, various options have been mentioned, as described below.

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<sup>1</sup>Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT registered trade mark).

<sup>2</sup> College of American Pathologists, United States of America and Connecting for Health, United Kingdom of Great Britain and Northern Ireland.

11. WHO develops its own international terminology. Although the creation of a global multilingual health-care terminology is feasible, it would require substantial resources and time and it would compete with the existing initiatives.

12. WHO does not become involved with the clinical terminology efforts. It would continue to develop classifications without recognition of terminology as an area for integration or for collaboration. In this case, it could invest its resources in other areas and maintain its neutrality towards any possible development. However, complications may arise in the future (e.g. lack of needed coordination between classifications and terminologies).

13. WHO takes part in the regulation of health information standards. 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 applies to any international health terminology such as comprehensiveness, adequacy, multilingualism, utility, reliability, validity, and interoperability which would improve the input from the health sector to the development of standardized terminologies. Current resources may however, be insufficient for this task.

14. WHO collaborates in various ways in the formation of an independent standard development organization. WHO may participate in the management board of the new organization and its regional structure, thus representing the interests of either all Member States or of developing countries that cannot become members in their own right. It could also participate in the harmonization board, leading the mapping activities between the systematized nomenclature and WHO's classifications. In this way, WHO would convey Member States' concerns and contribute to development of standardized global, multilingual health-care terminology harmonized with its classifications. This would, however, require substantial resources and would also require the approval of the Executive Board under Article 40 of the Constitution.

15. WHO becomes owner of the international systematized nomenclature of medicine. WHO would own the intellectual property rights over the nomenclature. The nomenclature could become a global standard, which raises questions of licensing, translation, and mechanisms for maintenance whereby Member States could influence future developments. Although this arrangement would work towards a global, multilingual health-care terminology, it will require substantial resources and will raise complex legal questions, that may pose difficulties for an intergovernmental organization such as WHO.

16. Other variants of these options could also be considered. In the light of views of the Executive Board, the Secretariat would envisage developing more detailed proposals. for WHO's role in this area.

## ACTION BY THE EXECUTIVE BOARD

17. The Executive Board is invited to note the report and to provide guidance on future directions for WHO in the development of standardized clinical terminologies.

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