

First edition
2002-02-15

Health informatics — Controlled health terminology — Structure and high-level indicators

*Informatique de santé — Terminologie contrôlée relative à la santé —
Structure et indicateurs de haut niveau*



Reference number
ISO/TS 17117:2002(E)

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Printed in Switzerland

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Foreword

ISO (the International Organization for Standardization) is a worldwide federation of national standards bodies (ISO member bodies). The work of preparing International Standards is normally carried out through ISO technical committees. Each member body interested in a subject for which a technical committee has been established has the right to be represented on that committee. International organizations, governmental and non-governmental, in liaison with ISO, also take part in the work. ISO collaborates closely with the International Electrotechnical Commission (IEC) on all matters of electrotechnical standardization.

International Standards are drafted in accordance with the rules given in the ISO/IEC Directives, Part 3.

The main task of technical committees is to prepare International Standards. Draft International Standards adopted by the technical committees are circulated to the member bodies for voting. Publication as an International Standard requires approval by at least 75 % of the member bodies casting a vote.

In other circumstances, particularly when there is an urgent market requirement for such documents, a technical committee may decide to publish other types of normative document:

- an ISO Publicly Available Specification (ISO/PAS) represents an agreement between technical experts in an ISO working group and is accepted for publication if it is approved by more than 50 % of the members of the parent committee casting a vote;
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An ISO/PAS or ISO/TS is reviewed after three years with a view to deciding whether it should be confirmed for a further three years, revised to become an International Standard, or withdrawn. In the case of a confirmed ISO/PAS or ISO/TS, it is reviewed again after six years at which time it has to be either transposed into an International Standard or withdrawn.

Attention is drawn to the possibility that some of the elements of this Technical Specification may be the subject of patent rights. ISO shall not be held responsible for identifying any or all such patent rights.

ISO/TS 17117 was prepared by Technical Committee ISO/TC 215, *Health informatics*.

Annex B forms a normative part of this Technical Specification. Annex A is for information only.

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Introduction

In 1839, William Farr stated in his First Annual Report of the Registrar-General of Births, Deaths and Marriages in England, "The nomenclature is of as much importance in this department of inquiry, as weights and measures in the physical sciences, and should be settled without delay." Since that time, this theme has been heard resounding from an increasingly large group of scientists (see Annex A). Today, the need for controlled terminologies to support health record systems has been widely recognized (E-1238, E-1239, E-1384, E-1633, ENV 12017). Controlled terminologies provide systems with the means to aggregate data. This aggregation of data can be carried out at multiple levels of granularity and therefore can enhance the clinical retrieval of a problem-oriented record, data pertaining to a classification for billing purposes, or outcomes data for a given population. Maintenance of large-scale terminologies has become a burdensome problem, as the size of term sets has escalated. Without a well-structured backbone, large-scale terminologies cannot scale to provide the level of interoperability required by today's complex electronic health record applications.

The solution rests with standards [7]. Over the past ten or more years, medical informatics researchers have been studying controlled terminology issues directly. They have examined the structure and content of existing terminologies to determine why they seem unsuitable for particular needs, and they have proposed solutions. In some cases, proposed solutions have been carried forward into practice and new experience has been gained.[8] As we have entered the twenty-first century, it seems appropriate to pause to reflect on this experience, and to publish a standard set of goals for the development of comparable, reusable, multipurpose and maintainable controlled health terminologies (ISO 12200, ISO 12620).

This Technical Specification is the first deliverable for the ISO/TC 215 *Health informatics*, Working group 3, *Health concept representation*, that is also working on an International Standard to be the basis for future standards in this area. It will serve as a guide for governments, funding agencies, terminology developers, terminology integration organizations and the purchasers and users of controlled health terminology systems toward improved terminological development and recognition of value in a controlled health terminology. This ISO/TS 17117 on quality indicators of controlled health terminologies is based on previous work in ASTM that naturally could not be harmonized with ISO work already in progress. The present work is therefore published as a Technical Specification at this time with the intent to revise it to be compatible with the planned basic terminology standard and converted to a full International Standard after a maximum of three years.