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Health informatics — Development of terms and definitions for health informatics glossaries

Informatique de santé — Développement des termes et définitions pour les glossaires d'informatique de santé

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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.

The procedures used to develop this document and those intended for its further maintenance are described in the ISO/IEC Directives, Part 1. In particular, the different approval criteria needed for the different types of ISO documents should be noted. This document was drafted in accordance with the editorial rules of the ISO/IEC Directives, Part 2 (see www.iso.org/directives).

Attention is drawn to the possibility that some of the elements of this document may be the subject of patent rights. ISO shall not be held responsible for identifying any or all such patent rights. Details of any patent rights identified during the development of the document will be in the Introduction and/or on the ISO list of patent declarations received (see www.iso.org/patents).

Any trade name used in this document is information given for the convenience of users and does not constitute an endorsement.

For an explanation of the voluntary nature of standards, the meaning of ISO specific terms and expressions related to conformity assessment, as well as information about ISO's adherence to the World Trade Organization (WTO) principles in the Technical Barriers to Trade (TBT), see www.iso.org/iso/foreword.html.

This document was prepared by Technical Committee ISO/TC 215, *Health informatics*.

This first edition cancels and replaces (ISO/TS 17439:2014), which has been technically revised.

The main changes are as follows:

— inclusion of procedures for governance in Clause 5 as these are now more clearly understood and tested at a high level.

— inclusion of reference to Dublin Core and how this document provides extended functionality to what is specified in it.

Any feedback or questions on this document should be directed to the user’s national standards body. A complete listing of these bodies can be found at www.iso.org/members.html.

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Introduction

General

Health informatics is serviced by multiple Standards Development Organizations, each with their own need for consistent definitions of the terms they use. The evolution of glossaries across these organizations has resulted in standards products where, increasingly, terms are defined and/or used in different ways. This situation leads to a lack of clarity in the use and meaning of health informatics around the world.

There are many national and international efforts to write and use clear standards to support the development of electronic health care initiatives. There are many standards and terms defined, however, finding the relevant standard, recording suggested improvements, and encouraging the use of standard terms is an ongoing issue to all involved in the development of these documents and in their use.

The Dublin Core Metadata Initiative has provided and continues to provide an excellent mechanism for documents, glossary metadata but was not found sufficient to meet the needs for harmonization between multiple divergent organizations.

This document provides details of the metadata and requirements for inclusion and construction of quality terms and definitions in health informatics glossaries. In the context of the recognized requirement for a single international health informatics glossary, the following are the purposes of this document:

— to collate relevant standards and guidance for the development of quality terms and definitions;

— to provide procedural standards for the introduction and management of terms in health informatics standards products in order to rationalize the use of these terms;

— to reduce the effort required for standards development to create and decide upon terms and definitions used in the documents produced by health informatics standards organizations;

— to support the development of international e-health initiatives through a consistent approach to development and use of terms and definitions.

Quality definitions and specification of additional metadata to explain and clarify terms used includes the following:

— consistent structure of terms, synonyms, and acronyms to support lookup;

— representation of definitions in a manner that is clear and fulfils the purpose of a definition;

— consistent provision and structure of metadata to explain further, provide examples and links to standards documents and standards processes to support maintenance of terms and definitions in an ongoing improvement environment.

The shared online tool of the Joint Initiative Council of Health Informatics Standards Development Organization's (JIC) that uses these metadata is the Standards Knowledge Management Tool Glossary (www.skmtglossary.org). The Standards Knowledge Management Tool (SKMT) is an Internet-based tool designed to assist in finding and managing standards documents, products, terms, and definitions. Each term and associated definition can be linked back to the document/s within which it is used (even if that link is simply to an organization's glossary).

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Health informatics — Development of terms and definitions for health informatics glossaries

1 Scope

This document provides details of the metadata and requirements for quality terms and definitions in health informatics for inclusion in health informatics glossaries.

This document does not cover specification of terminological content in systems, such as that represented in terminological resources, such as SNOMED CT, or, ICD. It is limited to concepts represented as terms and definitions included in standards.

This document is applicable to the following groups:

— Health informatics standards developers and standards development organizations.

— Developers, implementers, and managers of health information systems, clinical information systems, and clinical decision support systems.

— All users of health information systems clinical data, such as health statisticians, researchers, public health agencies, health insurance providers, health risk organizations, data analysts, and data managers.

2 Normative references

There are no normative references in this document.

3 Terms and definitions

For the purposes of this document, the following terms and definitions apply.

ISO and IEC maintain terminology databases for use in standardization at the following addresses:

— ISO Online browsing platform: available at https://www.iso.org/obp

— IEC Electropedia: available at https://www.electropedia.org/

3.1
abbreviation
designation formed by omitting words or letters from a longer form and designating the same concept

EXAMPLE HL7 is an abbreviation of Health Level Seven.

Note 1 to entry: An abbreviation does not define the meaning of the word it replaces; it functions as a specific type of synonym.

[SOURCE: ISO 1087:2019, 3.4.14, modified]

3.2
acronym
abbreviation made up of the initial letters of the components of the full form of the designation or from syllables of the full form and pronounced syllabically

EXAMPLE UNICEF - United Nations Children's Fund

[SOURCE: ISO 1087:2019, 3.4.15, modified]

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3.3
concept
unit of knowledge created by a unique combination of characteristics

Note 1 to entry: A concept can be represented using one or more terms, pictures, icons or sounds.

Note 2 to entry: Informally, the term "concept" is often used when what is meant is "concept representation". However, this leads to confusion when precise meanings are required. Concepts arise out of human individual and social conceptualizations of the world around them. Concept representations are artefacts constructed of symbols.

Note 3 to entry: Concepts are not necessarily bound to particular languages. They are, however, influenced by the social or cultural background, which often leads to different categorizations.

Note 4 to entry: For the purposes of health informatics glossaries, a term (in a given language and context) is considered to represent a concept uniquely.

[SOURCE: ISO 1087:2019, 3.2.7, modified]

3.4
context
universe of discourse in which a name or definition is used

EXAMPLE Noun, verb, country (e.g. UK), area of healthcare (e.g. Pharmacy), or organization (e.g. HL7).

Note 1 to entry: This definition differs from ISO 1087:2019 as there is a business need in the environment of standards development organizations sharing health informatics glossary content to make context explicit and to move towards having a single definition for a term in a specified context.

[SOURCE: ISO 14817-1:2015, 4.6, modified]

3.5
definition
representation of a concept by a descriptive statement that service to differentiate it from related concepts

[SOURCE: ISO 1087:2019, 3.3.1, modified]

3.6
designation
representation of a concept by a sign which denotes it

[SOURCE: ISO 1087:2019, 3.4.1, modified]

3.7
synonym
one or more words of the same language that have the same meaning in some or all senses

Note 1 to entry: A synonym replaces a word in a sentence and is of similar size to that word. It does not necessarily explain the meaning intended. A synonym is not a shortened form of the original word, such as an abbreviation.

3.8
synonymy
relation between or among terms in a given language representing the same concept

EXAMPLE Appendicectomy and appendectomy.

Note 1 to entry: Terms which are interchangeable in all contexts are called synonyms; if they are interchangeable only in some contexts, they are called quasi-synonyms.

[SOURCE: ISO 1087:2019, 3.4.23, modified]

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3.9
term
linguistic representation of a concept being defined in the glossary

Note 1 to entry: In this document, the word “term” is used to indicate term entry.

Note 2 to entry: A term can contain symbols and have variants, e.g. different forms of spelling.

3.10
family of terms
group of terms which define the attributes of related concepts.

Note 1 to entry: The terms in the family assists in the definition of other members of the family.

EXAMPLE The family of terms associated with Health records. The related terms in the family include, healthcare record, electronic health record, personal health record, medical record. Health records have attributes with include the specification of their ‘ownership’, e.g. medical records are owned and maintained by healthcare providers, while personal health records are maintained by the person to whom they pertain. Another common attribute is the format of the record, e.g. held in digital form – a digital health record. The term health record can be considered the least specific, healthcare records relate to the care provided in relation to health and could be considered a synonym of medical record, while electronic health record implies a format or functionality of the health record. Once health record is defined, it is easier to define healthcare record and electronic health record, as it is not necessary to define the base from which the definition begins.

Note 2 to entry: Guidance is provided later in this document on what terms are appropriate to a family. It is acknowledged that further testing of this process will be required through the implementation of this document.

4 Glossary management processes

4.1 Overview

A term can occur many times, each time with different identifying characteristics/metadata. These characteristics include: the definition of the concept that the term expresses (see 4.3), the description of context in which that definition applies (see 4.4), the original source of the definition (see 4.5), examples and comments on the use of the term (see 4.6).

To support harmonization, definitions in health informatics glossaries should be linked to the documents in which they are used. This can include a glossary of terms used by an organization or terms used in published standards (see 4.8). Metadata requirements to support glossary maintenance include categories for the status of the definition (see 4.9) and rationale for modifications made (see 4.12).

Definitions are linked to documents owned or created by standards development organizations. In the SKMT Glossary tool, organizations can determine their definitions and create their own glossary by searching by organization for terms linked to their documents. The processes of the SKMT Glossary are not defined here, as they are provided in detail in the User Guide.

The process for harmonization of terms/definitions in each individual standards development organization is different. Procedures are currently in trail and administered by the SKMT Governance Committee of the Joint Initiative Council of the Health Informatics Standards Development Organizations.

4.2 Term entry

The term is the word or group of words being defined in the glossary. An organizational health informatics glossary should include an entry for any term that would normally be included in terms and definitions or glossary section/s of a document or product. More extensive explanations of the principles and processes for development of quality definitions are provided in ISO 704. A summary of these requirements is provided here. ISO/IEC 2382 provides guidance on abbreviations, definitions, and representation, and though this relates more specifically to terminologies in general.

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