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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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ISO copyright office  
CP 401 • Ch. de Blandonnet 8  
CH-1214 Vernier, Geneva  
Phone: +41 22 749 01 11  
Email: [copyright@iso.org](mailto:copyright@iso.org)  
Website: [www.iso.org](http://www.iso.org)

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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](http://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](http://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](http://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](http://www.iso.org/members.html).

# 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](http://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]

### 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 Appendectomy 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]

**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.

A concept cannot be recorded without a term. A term entry is therefore a required element and should include any term that would normally be included in a terms and definitions or glossary section of a document or product.

A term is mandatory and should be (see ISO/IEC 11179-4)

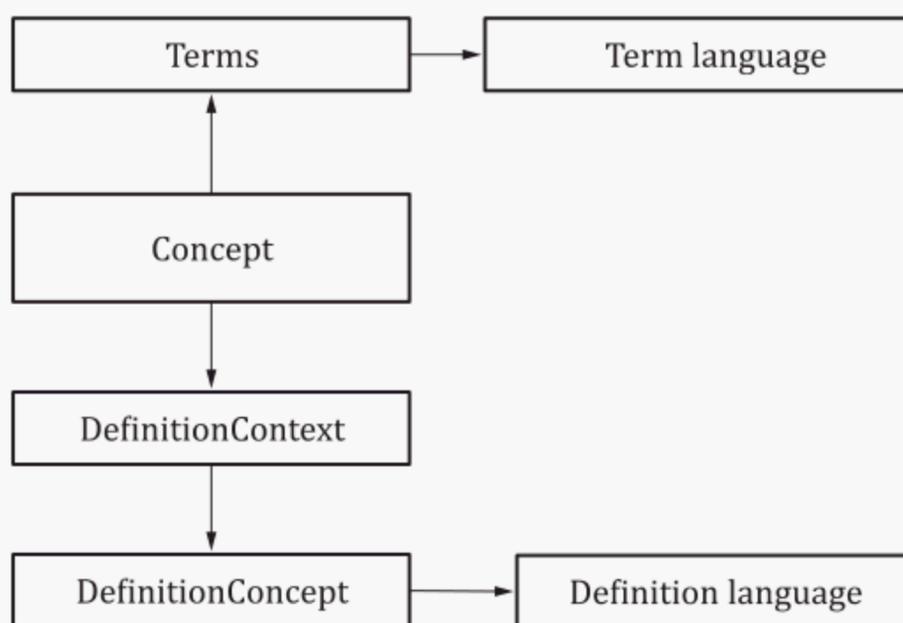
- a word or group of words,
- written in full,
- singular,
- in lower case throughout, and
- positive rather than negative, though negative terms may be included if essential to clear meaning.

For example,

- policy rather than the term policies, or
- electronic health record rather than EHR. EHR is an abbreviation of the term, not the term that should be defined.

An entry of the name of an organization is considered to be a different type of term. When the name is entered, it shall be written in full and the definition shall be a description of that organization, while the abbreviation or acronym of the organization should be listed as a synonym, abbreviation, or related term of the full term.

Terms can be defined in different languages. Where required, alternative forms of English can be indicated as specific languages (e.g. US English is not the same as English). [Figure 1](#) describes the structure of the linguistic components of the approach.



**Figure 1 — The relationship between the “core concept” and terms/definitions in other languages**

The term is the preferred term in the language being used. Synonyms, related terms, and abbreviations can also be included but are not the “core” term ISO 860 and ISO/TS 11669 describe principles in standards translation work.

### 4.3 Term definition

Each term entry can have many definitions, but there should be just one definition for a term in any given context. The definition is a textual description of the meaning of the term. Images are not part of the definition but may be included in the additional metadata describing the concept to describe more clearly what is intended.

Where a term is to be defined, this shall be done in consideration of not only this term but other terms to which this term relates (other terms in the family of terms). For example, do not define electronic health record alone. To accurately define this concept, it is necessary to understand the “family” to which it belongs. The electronic health record family of terms could include health record, healthcare record, medical record, and personal health record. The “family of terms” should be defined as a group rather than individually, as the understanding and consistent definition of the whole significantly improves the understanding and utility of the individual members of the family.

The definition shall (see ISO 704)

- a) Establish difference between existing concepts.

For example, what is the difference between terminological system and code system or classification system? The logical difference is that a code system is not necessarily human readable, i.e. a code system does not have to contain terms, while a classification is a terminological system but has additional characteristics for specific purposes in healthcare. These additional delimiting characteristics should be included and clear in the definition.

- b) define the concept, while the Usage Comment should give examples, and describe in more detail what is meant. Definitions shall not include long rambling examples or inclusions. Inclusion of examples and comments will make harmonization more difficult.
- c) Not include the term or its synonyms or abbreviations or other forms (noun instead of verb) in the definition.
- d) Use dictionary style when developing definitions. Phrases such as “Word means” or “This describes a situation” should not be used in definitions nor should definitions be full sentences or explanations.
- e) Use correct grammar. For example, write the definition to match the part of speech. If the term is a verb, the definition will probably begin with “to” while nouns are likely to begin with “a” or “the”.
- f) Use simple language. For example, “use” rather than “utilize”. Where there is a highly complex definition used by a specialist area of the community, the context shall be clearly stated. If the definition is formal using language which is understood by the intended community, consideration should be given to a simple, plain language version of the definition which can be understood by a broader community. The simple definition should be the one used as the “core definition”, the one used across all contexts.
- g) Be able to replace the term in context (the substitution principle). Additional information shall be given only in the Usage Comments as examples or notes to the entry. For example,
- 1) The definition of terminology can be: structured human-readable and machine-readable representation of concepts and relationships,
  - 2) The definition of mapping can be: The process of associating concepts from one terminology to concepts in another terminology.
  - 3) Can the definition of terminology be used in the mapping definition and have meaning retained?

The process of associating concepts from one structured human-readable and machine-readable representation of concepts and relationships to concepts in another structured human-readable and machine-readable representation of concepts and relationships.

In this definition, the replacement of the word terminology works well and therefore, this definition of terminology meets the requirement of being able to appropriately replace the term in a sentence.

- h) Be a single phrase specifying the concept, and if possible, reflecting the position of the concept in the concept system.

#### 4.4 Context description

This makes the situation or organization to which this definition of the term applies clear. This is also called specialization context. This is a free text field that is required to differentiate between multiple standard (category) definitions of a single term.

Context description should only be included if this definition of the term is for a specific purpose and not applicable throughout all areas of health informatics. Context should be described clearly, and an example should be provided to ensure intelligibility to all readers, recognising that not all readers are technical or specialists in the area concerned.

Categories to represent context are needed. The data collection of glossary content is not yet broad enough to support such classification. It is the intention that a classification be developed using content from the term and definition harmonization process and the extending data captured in the SKMT.

In the SKMT tool, the word context means context description. Indication of context is optional.

#### 4.5 Source

This is a reference to the original source of the definition. This does not mean just the document in which the definition is used, as there might be many of these, but the original source of the definition where it is known. Source should be provided wherever possible, though previously published standards might not always indicate the original source and in this case, rather than indicate an incorrect source, it should be left alone. It should be noted that the use of a definition within a published standard shall always be indicated. As a minimum, this will link to the glossary of a given standards development organization.

For example, a term might have been defined and that term/definition is used in four different published standards of different standards development organizations.

Document A — the original document using this definition, i.e. where this definition was “created” or first published. This document might or might not be a standard.

Standard B — references Document A for the definition

Standard C — references Standard B for the definition. This is not correct. The reference should be to Document A but the nature of standards development and the lack of historic consistency in referencing can make this difficult. It is not suggested that effort should be made to correct past errors, rather that health informatics glossaries move forward using improved procedures.

Standard D — a new document - should reference Document A as the source of the definition.

There is a difference between the source of the definition and the document in which the definition is used.

In the example above, Standard B, Standard C, and Standard D all use the term/definition but none are the source of that definition.

The source should be represented using Harvard reference style or the relevant SDO's style.

#### 4.6 Usage comment

Description of how this term is used, including examples and notes. This is free text, can be blank, and can include comments from more than one standards development organization.

#### 4.7 Image

This is an option to record an image that which enhances or explains more fully the definition or examples of the term in use.

#### 4.8 Document(s) in which the term/definition is used

All terms and definitions should be related to at least one document. If an organization is not recording standards and products in the SKMT, a single document called “organization glossary” should be created to which all terms used in the glossaries of that organization can be referenced. This supports the creation of an extract glossary for that organization.

#### 4.9 Status of the definition

Indicates the stage of publication or use of the definition. These status categories have been taken from ISO/IEC 11179-4:2003.

P – Pending – current work occurring on the definition – it is not final. This status is established by the publishing or developing organization.

C – Candidate – definition appears in a published standard or product but has not yet been harmonized across all member organizations of the Joint Initiative Council. This status is established by the publishing organization. If they have published the product, they may put that definition forward as a candidate “standard” definition.

S – Standard – definition has been harmonized and confirmed by the health informatics standards development organization community as the agreed definition in this context. Standard status is established by agreement of the members of the Joint Initiative Council – SKMT Governance Committee.

R – Retired – definition has been replaced by a confirmed/harmonized definition for the same concept or is no longer used. A retired status may be used by the following:

- the publishing organization (if they are the only organization using this definition in this context to indicate that they no longer actively use the definition.
- the SKMT Governance Committee where a term is retired as part of the term/definition harmonization process. The intention is the same, which is to indicate that this definition is no longer the definition supported by the health informatics standards community in this context.

Every term shall have a category. When entered into the system, users may only indicate that a definition is a candidate or a pending term. The glossary administrator is responsible for recording that a term is to be considered a standard or has been retired.

The term “category” has been used as different health informatics bodies use these terms differently and there was a desire to differentiate between the intent in a shared glossary in particular, and glossaries in general, rather than in standards documents.

#### 4.10 Version

Number indicating the sequence of the version of the definition. The highest number is the most recent. This number is automatically generated by the SKMT glossary but can be optional in other systems used to collect and represent this data.

#### 4.11 Version date

The date upon which the version of the definition changed. This data is updated automatically in the SKMT glossary but can be optional in other systems used to collect and represent this data.

#### 4.12 Rationale for change

Where the category, content, or structure of the definition and its associated metadata, including comments, are changed, the reason for the change shall be documented. This supports improved understanding of the logic behind any change and reduces later circular arguments for change.

## 5 Governance

The health informatics community seek a consistent and clear repository for terms and definitions used in health informatics standards. A shared repository effectively provides a health informatics shared glossary. The governance of such a repository shall include:

- fair and non-discriminative representation of all contributing organizations
- Sharing of suggested definition improvements and context declaration between all contributing organizations, giving the opportunity to harmonize those terms and definitions.
- A register of requests and suggestions for modification, which are collaboratively addressed and prioritized.

## Bibliography

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- [8] ISO/IEC 11179-4, *Information technology — Metadata registries (MDR) — Part 4: Formulation of data definitions*

