AS 5021—2005

Australian Standard™

The language of health concept representation

STANDARDS AUSTRALIA

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PREFACE

This Standard was prepared by the Australian members of the Joint Standards Australia/Standards New Zealand Committee IT-014, Health Informatics. After consultation with stakeholders in both countries, Standards Australia and Standards New Zealand decided to develop this Standard as an Australian Standard rather than an Australian/New Zealand Standard.

The objective of this Standard is to provide agreed definitions of terms used for health concept representation in Australia and a coherent vocabulary of the central concepts of terminology. It is intended for the general health informatics and health information community as a clear way to support practical developments by allowing clearer language to be used in discussion of health concept representation and to avoid ambiguity.

This Standard is designed to complement ISO Standards by extending and clarifying the meaning of terms. This Standard is not all-inclusive. It is envisaged that it will develop over time to meet ongoing needs. Readers are invited to identify and notify Standards Australia of additional terms that should be included. Some of the items intended for inclusion in the next version will include UML modelling of the concepts included in this document.

This document attempts to use plain English and examples to help describe concepts, which may be technically defined elsewhere. These concepts are often used in a manner, which is inaccessible to the health community because of its technical nature and assumed knowledge. Committee IT-014 have however made reference, where appropriate, to these sources. One of the sources is ISO/DIS 17115, *Health informatics—Vocabulary for terminological systems*, which had not been published at the time of publication of this Standard.

The terms ‘normative’ and ‘informative’ have been used in this Standard to define the application of the appendix to which they apply. A ‘normative’ appendix is an integral part of a Standard, whereas an ‘informative’ appendix is only for information and guidance.

CONTENTS

FOREWORD

TERMINOLOGY IN HEALTH CARE

The language used in health care is complex and multifaceted, more so than most language domains. In fact, looseness in the usage of words such as terminologies and classifications tends to confuse discussion and debate. It has been estimated that between 500 000 and 45 million different concepts are needed to adequately describe concepts like conditions of patients and populations, actions in health care and related concepts, such as biomedical molecules, genes, organisms, technical methods and social concepts.

Simple coding schemes are inadequate to represent and especially to process this complexity, and formal multidimensional concept representation systems are required. Several such formal systems exist but systems and underlying philosophy are described in different ways. The system itself can, for example, be called an ontology, medical entity dictionary coding and reference model or reference terminology. The differences in terminology are understandable—this kind of work is highly interdisciplinary and integrates knowledge from linguistics, philosophy, informatics and health sciences, and there is room for misunderstanding between disciplines.

ISO/DIS 17115, *Health informatics—Vocabulary for terminological systems* provides detailed technical definitions that have not been included here. The intention in this Standard is to retain the meaning inherent in the technical definitions in ISO/DIS 17115 while offering extended plain English examples and descriptions.

KEY FUNCTIONS OF TERMINOLOGY

While accepting that information management is a broader issue than the introduction of computers for information processing and communication, this Standard does focus on the terminology requirements for electronic information management. This document represents a major infrastructure requirement for the development of electronic data collection, storage and retrieval systems and to support the communication of health information using technology. Figure 1 indicates the central nature of the need for formal representation of information in the technological environment.

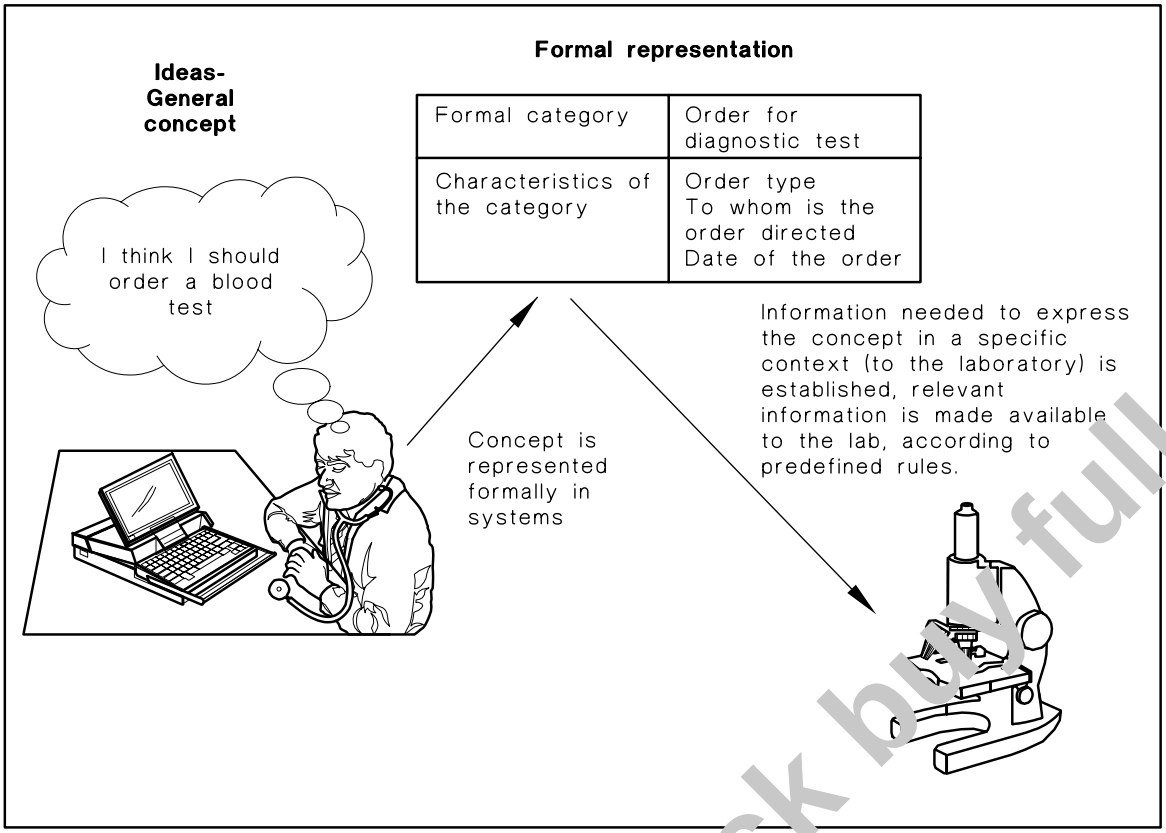

FIGURE 1 CONCEPT FORMAL REPRESENTATION

Health concept representation is a field, of which terminology is a component. Health concept representation includes rules and relationships that are used to interpret clinical terms within confined contexts. The context in which an item of clinical information is represented can dramatically affect its meaning or semantic value. Similarly, representation of a measurement in red in a report may have meaning, signifying that it is out of its agreed normal range.

Figure 2 is a Venn diagram that indicates very generally the scope of health concepts and various ways of representing these concepts and the intersections used in this domain. The figure attempts to illustrate the overlapping nature and complexity of the various aspects of health concept representation; However, the size of the set in the diagram does not indicate the actual size or importance of the set, but simply the relationship representation.

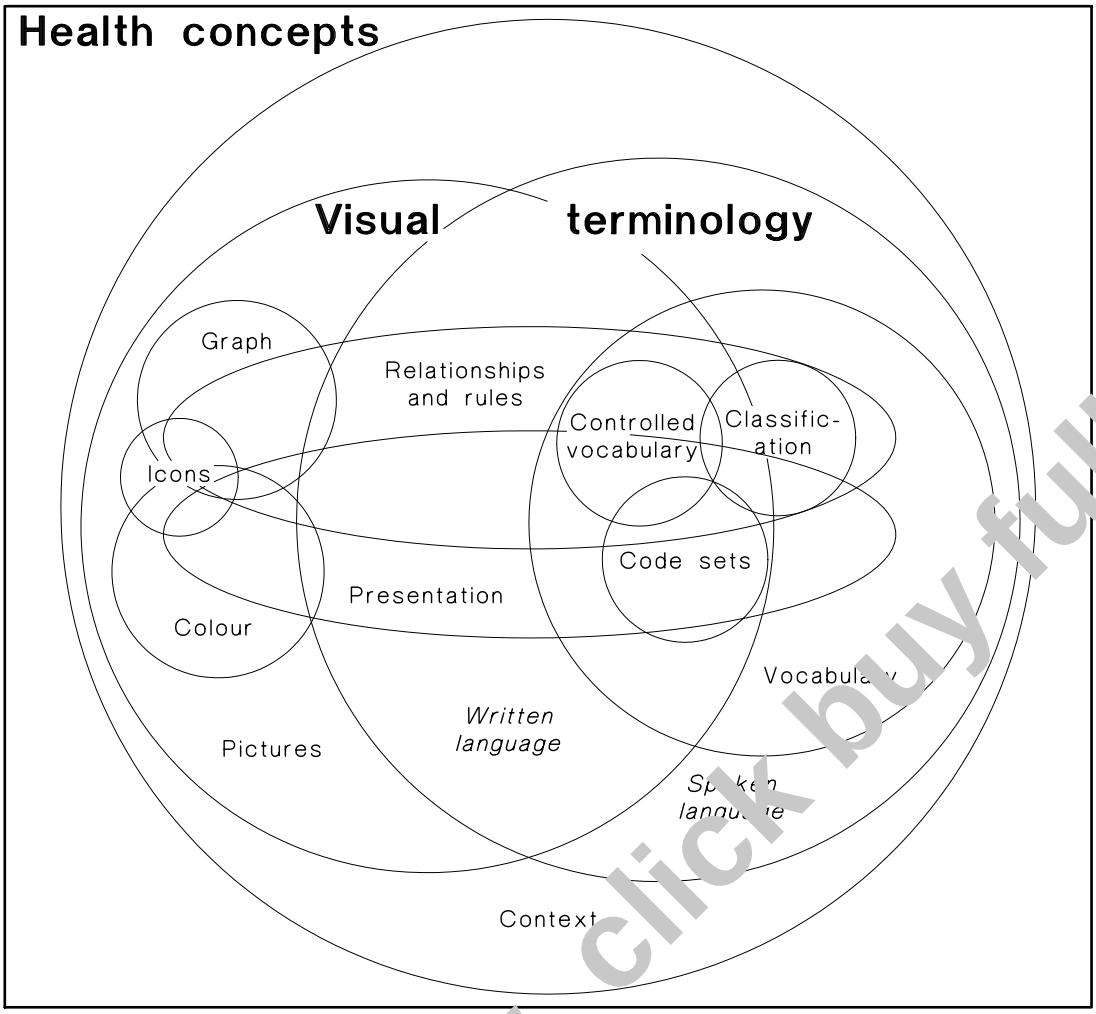

FIGURE 2 PICTORIAL REPRESENTATION OF MAJOR ELEMENTS OF HEALTH CONCEPT REPRESENTATION.

Health care is a data, information and knowledge intensive industry. Safe, effective and efficient care is dependent upon accurate and detailed clinical information being reliably communicated, unambiguously interpreted and accurately transformed from data into knowledge.

Increasingly, health jurisdictions and organizations are planning and using point of care clinical information systems including those derived from electronic health records to improve this communication and connection across service and other traditional boundaries. The primary motivation for the current level of interest in terminology is about the imperative to reliably re-use concepts clinically and for reporting. (Preserving meaning).

However, clinical information is very complex, and its electronic communication requires disciplined approaches to capture, storage, transformation, presentation and exchange including agreement on the ways in which it will be represented.

'Any meaningful exchange of utterances depends on the prior existence of an agreed set of semantic and syntactic rules'.[1]

[1] ISO TR 9007:1987, *Information processing systems—Concepts and terminology for the conceptual schema and the information base.*

In short, terminologies and classifications form the 'language' of health care, and are fundamental enablers of health information interchange and aggregation. Standardization of concepts and their representation is a prerequisite to electronic support for care across settings, professions, jurisdictions and other potential barriers, and to the assimilation of data, information and knowledge around individual patients and clients. Current and impending rapid escalation of electronic interchange provides an urgent driver for standardization.

NEED FOR HEALTH CONCEPT REPRESENTATION

Health care has an enormous language. Hundreds of thousands of concepts are used by clinicians and that number grows each year as knowledge advances and conditions acquire new names. The large number of synonyms, acronyms and variants found within clinical records is one of the key reasons health data are difficult to manage. This variance in language results from differences in professional, cultural, educational, organizational, local, regional and national backgrounds.

Health care process redesign, however, is often dependent on new information flows across traditional boundaries. Increasingly, health care providers are reliant on information originating outside their own control. If this information cannot be meaningfully and contextually interpreted, including by computers as well as humans, then the risk of adverse consequences will remain high and the potential for efficiency improvements will not be realized.

In practice, there are large numbers of clinically related classification systems, data dictionaries, terminologies, vocabulary lists, code sets, etc. For example, HL7 (an international health information standards development organization) has identified over 400 different coding systems currently associated with its messaging standards. These may be—

(a) highly specialized, disease or domain specific or very general and comprehensive;

(b) designed for a variety of specific purposes and structured in a variety of ways; and/or

(c) originating from, and thereby embodying, different philosophies/approaches to health care.

A coherent approach to health concept representation has the potential to underpin a range of health care benefits including:

(i) *Consolidation of person-level data into electronic health records, including virtual records* Systematic approaches to managing disparate 'languages' within longitudinal, consolidated records, will be required in order to realize the benefits of EHR's.

(ii) *Meaningful interpretation of terms from one system by another* Collection of data multiple times for multiple purposes is inefficient, costly and risky. Data must be re-useable and serve all purposes, and the way data concepts are represented is a fundamental determinant of the capacity to do this.

(iii) *Enabling the creation and application of clinical queries and rules, supporting clinical decision support* Clinical rules can only be applied, in particular by automated systems, if the rules are expressed in terms of concepts which have meaning in terms of the way patient data are captured and stored. The benefits of guidelines and other decision support tools will depend on the use of common terms and concepts in both patient records and knowledge support resources.

(iv) *Standardized encoding of information at the point of care* An integrated approach linking terminologies with classifications opens the door to greater automation, with both efficiency and data quality improvement potential. With the introduction of coding in emergency departments and other settings, traditional (after the event) approaches to coding are likely to require supplementation in order to cover the volume of episodes.

(v) *Analysis of clinical outcomes* Consistent terminology usage can help to improve clinical outcomes both by facilitating patient care processes and by aggregation or classification of concepts enabling measurement at a variety of levels.

(vi) *Development of intelligent privacy, confidentiality and security systems* In an environment in which certain data is masked for certain purposes, the protection of consumer privacy can be expected to present significant technical problems. Automated support can be enhanced via the application of sophisticated rules, but this is once again dependent on a high degree of coherence between the concepts embodied in rules, and those represented in patient data.

(vii) *International trade* Health software imported into or exported from Australia should embody internationally standardized health terminology so as to reduce the costs of subsequent customization.

Standardized health concept representation is required across the spectrum of information types. These may be defined in a variety of ways, but will include personal health data (e.g. risk factors, allergies), process of care (e.g. diagnoses, medications, investigations), and outcomes.

STANDARDS AUSTRALIA

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1 SCOPE

This Standard lists definitions, explanatory notes and examples of common terms used for health concept representation by the health informatics community in Australia.

This Standard is intended to —

(a) support communication between health service providers and technical system developers;

(b) support computer integration and information comparability; and

(c) clarify the language of health informatics in education.

2 APPLICATION

This Standard is intended for application by the following users:

(a) Health service providers wanting to use health concepts and to support communication with technical system developers.

(b) Health information managers.

(c) Government and health funding agencies.

(d) Terminology (health language) developers.

(e) Data developers (including data set developers) and data analysts.

(f) Data modellers and analysts.

(g) Educators.

3 REFERENCED DOCUMENTS*

The following documents are referred to in this Standard:

ISO	
1087	Terminology work—Vocabulary
1087-1	Part 1: Theory and application
2382	Information technology—Vocabulary
2382-4	Part 4: Organization of data
TS 17117	Health informatics—Controlled health terminology—Structure and high-level indicators
TR 20514	Health Informatics—Electronic health record—Definition, scope, and context
ISO/IEC	
11179	Information technology—Metadata registries (MDR)
11179-1	Part 1: Framework
11179-3	Part 3: Registry metamodel and basic attributes

* Appendix A lists bibliographic details of documents other than the Standards listed in Clause 3, which provided information reproduced in this Standard.