SNOMED International Position on the addition of “Patient-friendly terms” (PFT) to the International release of SNOMED CT

Version 1.0

Introduction

There has recently been a call from some members for the addition of “Patient-friendly terms” to SNOMED CT to support consumer health applications. This brief is a summary of discussions held by the Editorial Advisory Group. Additional review was made by the Content Managers Advisory Group at the April 2017 Business Meeting in London related to the benefits and detriments of inclusion of this type of description to the International release and the position that SNOMED International will take regarding requests to add this type of content.

Background

“Patient-friendly terms”, otherwise known as “consumer health vocabulary”, “patient-friendly terminology” may be defined as: “…informal, common words and phrases about health… It [may] include jargon, slang, ambiguous, and misspelled words as used by consumers and health care professionals.”

According to the report from Semantic Health Net [2], consumer friendly terminology provides benefit in at least three areas:

- Information Retrieval - facilitates automated mapping of consumer-entered queries to technical terms, producing better search results
- Medical Records - medical records and test results available to Patients frequently contain jargon. A CHV (consumer health vocabulary) can represent terms with consumer-understandable names to help patients better interpret the medical concept
- Health Care Applications - patients may enter consumer expressions such as “nose bleeding” or “cluster headache”, the CHV would facilitate automated mapping of these expressions to technical concepts (e.g. “epistaxis” and “histamine cephalalgia”)

There are a number of efforts to create consumer health terminologies, such as the Wellmed Consumer Health Terminology [3]; the Italian Consumer-oriented Medical Vocabulary [4]; the Consumer Health Vocabulary Initiative [5] and others. For the most part, these are based on the Unified Medical Language System and its component terminologies and use a standard terminology such as SNOMED CT as the “source of truth” for the meaning of the medical term.

One of the major issues surrounding the use of PFTs is the ability to determine the semantic equivalence with standardized clinical terminology. Patient-friendly terms generally fall into four categories:

- exact match; the PFT has exact correspondence to a term in the standard resource and both have the same meaning;
- synonymy; the PFT does not exist in the standard resource, but corresponds to a technical term that denotes the same concept;
- hyponymy; the PFT is considered as term of inclusion of one or more concepts in the standard resource (AKA narrower than);
- hypernymy; the PFT includes in its meaning one or more terms in the standard resource (AKA Broader than)

When PFTs are mapped to standard terminologies, there is often a 1:N relationship, where a single PFT is mapped to multiple terms in the reference terminology. While from a consumer point of view, this provides some benefit, when the PFT is used as the source term for analysis, the actual intended meaning of the term is not always apparent. As stated in the semantic net analysis “…patients often create semantic ambiguities in using lay terms for expressing clinical concepts, in fact they use some terms interchangeably as synonyms (as in the case of headache and migraine) making errors.”

Benefits of Patient-friendly terminology in the International release of SNOMED CT

- Availability of “familiar” terminology to users with less knowledge of clinical terms
- Ability to link “non-professional” jargon with more specific clinical terminology.
- Removal of data-recording obstacles when a familiar term is not available for users to select from.

Detriments of Patient-friendly terminology in the International release of SNOMED CT

- PFTs may be ambiguous, and while duplicate descriptions are allowed in SNOMED CT, the presence of these terms within the same hierarchy makes it difficult to determine which concept the PFT actually refers to
- The potential number of PFTs for a given concept is unbounded. Consumer terminology is often regionally and lexically idiosyncratic. The maintenance of idiosyncratic or colloquial terms would be unmanageable without clear criteria for acceptance.
• Consumer level terms are often nationally, regionally or culturally context sensitive. The same term might mean substantially different things in these different contexts. Trivial examples include the term “tomato sauce”, which in the UK means what the US calls “catsup”; or “Pavement”, which means the road surface in the US and Canada and the sidewalk in the UK. This context sensitivity provides many opportunities for erroneous usage of clinical terms.

Underlying assumptions related to the proposed SNOMED International position on PFTs in the International release

• Patient-friendly terms would only be included in the International release as US or GB English, thus not supporting International consumer terminology
• The potential set of patient-friendly terms is relatively unbounded and may include abbreviations and acronyms that would be in conflict with SNOMED Ct editorial policy
• The SNOMED CT extension and refset mechanisms were originally created to support multi-lingual and context dependent dialect use cases for linkage to the international content.
• The International release of SNOMED CT does not currently have a way of assigning a description as "equivalent to" or "broader than" the concept that it is related to

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SNOMED International encourages the addition of Patient-friendly vocabulary to extensions. The International Release of SNOMED CT will accept "patient-friendly" descriptions when they coincidentally adhere to the criteria for addition of descriptions as described in Section 7.2 of the SNOMED CT Editorial Guide.

SNOMED International guidance for the use of Patient-friendly terminology in SNOMED CT extensions and refsets.

The SI Education and Product Services team are working on a 'Practical Guide to Extensions' during 2017. The EAG requested guidance on addition of patient friendly terms in extensions be included in the 'Practical Guide to Extensions' and also expressed a strong interest in reviewing draft guidance on this topic. The EAG also indicated a preference for this guidance to utilize the existing dialect and language mechanisms (i.e. Language Reference Sets) for this purpose.

References