Preparation for electronic health records

Standardizing terminology

The global move towards electronic health records (EHRs) and the need to make data available for wider purposes, including research, registries, commissioning and other secondary uses, brings with it a requirement to standardize the way we record data in routine clinical practice. Traditionally clinicians have been able to resolve variations in terminology by intuitively acknowledging that, for example, RA and rheumatoid arthritis are the same disease. These types of understanding will not survive the transition to EHRs.

It is time to build on previous work [1, 2] and develop a standard terminology set (STS) for rheumatological disorders that can facilitate large-scale data sharing, aggregation and analysis using data collected during routine clinical care. This is a two-stage process. The first stage is to agree on the set of concepts so that any disorder can be assigned to one, and only one, concept. This task crosses specialty boundaries as well as national and linguistic borders. There needs to be a clear distinction between disease concept and disease phenotype, particularly for multisystem diseases. For example, the concept RA describes a disorder characterized by symmetrical inflammatory polyarthritis with involvement of the hand and wrist. Its features may include the presence of RF, ACPA, rheumatoid nodules, vasculitis and so on. It would be a mistake, however, to create separate concepts for all possible combinations of these features. There are better methods for capturing phenotypic details of complex diseases. These comments illustrate the tension between combining disease features, which leads to a limited terminology based on broad concepts, and splitting, which leads to a much finer level of detail in each concept. Given the impossibility of capturing all phenotypic variation in a manageable set of clinical terms, we would favour a sparser, less specific approach, with minimum core data sets to capture phenotypes.

Having agreed the set of concepts, the next stage is to agree clinical terms to describe these concepts. Currently the most comprehensive systematically organized set of clinical terms is the Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) [3]. It is designed to support data captured at the point of care and allows subsequent machine processing. Its concepts are arranged into domains that include disorders, symptoms and findings as well as health care procedures and interventions. The hierarchical structure of SNOMED CT allows data to be analysed directly, while the development of cross-maps to classifications such as the International Statistical Classification of Diseases and Related Health Problems, 10th Revision allows SNOMED CT-encoded data to be transformed into schemes already in use. For each concept there is a preferred term and in many cases one or more permitted synonyms. SNOMED CT has been translated into several languages. The concepts, however, are language independent and it therefore offers a system for international data recording and sharing. Any STS for musculoskeletal disorders should have a full SNOMED CT mapping. Analysis of the October 2013 UK edition of SNOMED CT [4] indicates that in order to achieve such a mapping, changes will need to be made to SNOMED CT’s content, contributing to ongoing quality improvement activities.

Addressing missing content: SNOMED CT is incomplete. This incompleteness is due in some cases to the inability of the existing SNOMED CT to capture new concepts. This is true for newly described diseases such as IgG4-related diseases or those that have been subject to reclassification within the past few years, the systemic vasculitides, for example. Elsewhere, gaps can be found in the representation of more established conditions. For instance, there is currently no SNOMED CT term for oligoarticular PsA.

Addressing inconsistent and atypical use of terms: SNOMED CT was formed from the merger of several prior terminologies. Consequently term use is not consistent. For example, there is no agreement on whether arthritis should be preferred to arthropathy, illustrated by reactive arthropathy of the knee being a subclass of arthritis of the knee. Likewise, there are variations in syntax and word order, e.g. diffuse systemic sclerosis as compared with systemic sclerosis, limited.

Addressing errors of commission: SNOMED CT contains errors of commission by virtue of either inappropriate hierarchical associations of content or the application of incorrect descriptions. For example, arthritis mutilans has a SNOMED CT synonym of psoriatic arthritis, destructive type, but it is represented as a subtype of RA in the SNOMED CT hierarchy. Furthermore, the only available broad term for PsA is psoriasis with arthropathy, which presupposes the presence of the skin disorder.

Systematic comparison of SNOMED CT with the content requirements identified during the development of the STS for rheumatological disorders allows changes to be made that will address errors in the above patterns, progressively improving the analytical capabilities of SNOMED CT.

We advocate the adoption of existing SNOMED CT terms where these are correct and familiar to clinicians.
Where no appropriate term exists, new terms can be created and submitted for inclusion in SNOMED CT. Where necessary, SNOMED CT synonyms can be promoted to a preferred term status and hierarchical assertions corrected. The British Society for Rheumatology (BSR) Informatics Group has demonstrated the feasibility of this approach by producing a draft set of clinical terms for inflammatory arthritis and CTDs. Working with the UK Health and Social Care Information Centre (HSCIC), a small number of new terms and modifications were submitted for SNOMED CT editorial review and have been published in the April 2014 UK Clinical Edition [5]. A rheumatology provisional subset will be published to identify the composition of this approved set and distinguish the preferred terms. Some contentious issues remain, which will require wider consultation, but the end result will be an agreed set of concepts and their clinical terms capable of capturing diagnoses of inflammatory arthritis or CTD. This process will soon be extended to other disease areas, eventually producing a complete STS for rheumatological disorders. Importantly, this STS will be subject to iterative review to ensure continued currency.

The complexity of the task should not be underestimated, but the reward for success will be a much better ability to share data nationally and internationally, capture clinical phenotype and inform decisions, which will influence the future shape of rheumatology services.

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