Empowering clinical data collection at the point of care

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INTRODUCTION

Collecting clinical data has huge benefits, and many bespoke systems have been well supported by clinicians with outputs leading to improved care.[1] The National Health Service (NHS) has one of the most comprehensive data collection systems for inpatients in the world (Hospital Episode Statistics). Although the data are used extensively for commissioning and NHS management, few clinicians find the data either accessible or useful.[2] This is unfortunate because potentially quality indicators[3] could be developed that would significantly enhance quality of care and patient safety. Clinicians have not generally engaged with these data because it is normally extracted after the episode of care from unstructured notes and recorded using the International Classification of Diseases V.10 (ICD-10).[4] The end result is deemed too inaccurate for clinician-led research, audit or quality improvement. In truth the data quality is normally good but not sufficiently granular for this type of clinical analysis. A further problem is the lack of clinical information recorded in outpatients, especially for specialties like community paediatrics that are now almost entirely outpatient based.[5]

Comprehensive high-quality clinical data require the involvement of clinicians on a daily basis at the doctor–patient interface. As clinicians are pressured for time, they will only be able to achieve this goal if provided with an appropriate tool. Furthermore, for national comparison, it is essential that a spade is always a spade and a shovel a shovel; in other words, there has to be clear agreed and published definitions.

SNOMED – CLINICAL TERMS

The NHS is signed up to a terminology that is appropriate for clinicians to use, especially when delivered using electronic systems.[6] The Systemized Nomenclature of Medicine – Clinical Terms (SNOMED CT) was created by amalgamating the American Pathology terms of SNOMED-Reference Terms and Read Clinical Terms V.3.[7] Read terms were developed by a general practitioner, James Read, and are still widely used in general practice systems; they were extended under the clinical terms project to provide Read V.3. Many will remember the paediatric adaptation of ICD-10 that were published by the British Paediatric Association in a red book and online.[8] This was developed with a grant from the Department of Health and was designed to do for paediatrics what Read was doing for general practice. Unfortunately, these terms were never incorporated into Read or SNOMED CT or embedded into hospital data collection systems, although many local systems made use of this resource.

SNOMED CT allows clinicians to use their preferred diagnostic and procedure terms and can be as granular as necessary to distinguish similar conditions and treatments. The language is appropriate for use in all clinical correspondence. It supports the Clinical Headings project run by the Academy of Medical Royal Colleges (AOMRC) and the Health Informatics Unit of the Royal College of Physicians.[9] Furthermore, SNOMED CT can be mapped to ICD-10 for diagnosis and the Classification of Interventions and Procedures V.4 for procedures. Mapping is often on a many-to-one basis as a consequence of the greater specificity of SNOMED CT. Consequently, the aspiration to collect *data once and use for many different purposes* can start to be realised.[10]

SNOMED CT has a structure that is designed to reduce ambiguity and to facilitate subsequent data analysis. Online tutorials and webinars[11] explain the 19 different SNOMED CT hierarchies and the 'IS-A' parent–child relationships. Each unique SNOMED CT concept (equivalent to a clinical thought) has a Concept ID Number, a fully specified name, a preferred term and a number of synonyms where required. The fully specified name describes the clinical thought and will always indicate the hierarchy in brackets. Clinicians will mainly use the Clinical Findings (includes diseases and symptoms) and Procedure hierarchies, although others exist to cover areas such as descriptions of body parts, social context and even UK administrative concepts. Figure 1 shows the IS-A or parent–child relationships for bacterial pneumonia; the relationships mean that bacterial pneumonia will be found if exploring either infectious diseases or diseases of the respiratory system. The hierarchy can be as detailed as necessary for the given specialty so that in paediatrics bacterial pneumonia would be further subdivided to include, among others, acute lobar pneumonia and staphylococcal pneumonia as distinct diagnostic categories. The preferred term or an appropriate synonym will normally be used in clinical correspondence.

Fortunately, the complexity of the structure need not concern clinicians using the terms; powerful search facilities will allow the required term to be found quickly. Also, a list of commonly used favourite terms can be developed within many Electronic Patient Record (EPR) systems to facilitate rapid data recording. However, the effectiveness of any search facility is tempered by the content so that a simple search might result in too many terms, outdated terms or overlapping terms where the concepts have not been accurately defined.

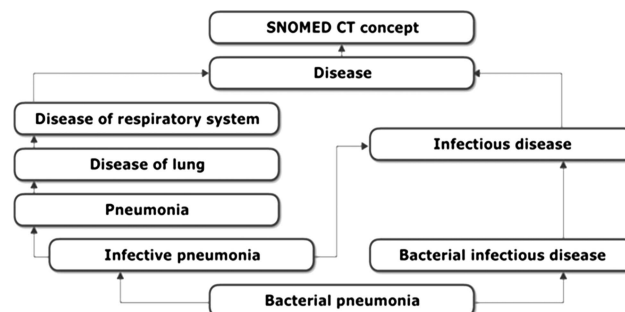SNOMED CT content has not yet been sufficiently developed to meet the full

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Figure 1 'IS-A' relationships in Systemized Nomenclature of Medicine – Clinical Terms (SNOMED CT). This is an example of the 'IS-A' relationships where multiple hierarchies are used.

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needs of all hospital specialties including paediatrics. For example, a project in adult rheumatology[12 13] found that essential concepts were missing; others that were present were incorrect. Either the preferred name was inappropriate, or there were incorrect synonyms or the hierarchy was wrong. Some terms needed to be retired because they were based on outdated or misconceived concepts. However, SNOMED CT is a dynamic terminology and has now been updated; an important outcome of the project.

The number of concepts in SNOMED CT is very large because it provides a single vocabulary for all healthcare requirements. Searching 400 000 terms presents difficulties because a concept that is essential for one specialty may be inappropriate for another. A paediatrician will not be able to distinguish the number of varieties of middle ear disease required by an ear, nose and throat surgeon; acute and chronic otitis media is probably all that is required. Similarly, a Foundation Doctor searching for asthma may be presented with >70 different terms, the vast majority of which are not relevant to an acute paediatric admission. Consequently, it is necessary for each specialty to identify the terms they require and have these presented as a subset that are consistent nationally across the specialty.

The UK Terminology Centre is able to publish subsets so that they can be delivered within a SNOMED CT browser or search function in an EPR. Much is currently changing in the world of informatics; there is a new imperative for Trusts to be using an EPR by 2018.[14] It is almost certain that NHS England will require clinicians to use SNOMED CT to record diagnosis or symptoms and procedures; the genome project is requiring phenotype data to be recorded using SNOMED CT. Unless specialty groups within the colleges ensure SNOMED CT is tailored for their specialty, its use will be cumbersome, confusing and add very little value to ICD-10. On the other hand, there is the potential for clinicians to have access to high-quality national data for research, audit, quality improvement and revalidation.

THE PAEDIATRIC DISABILITY PILOT
To encourage the development of appropriate terminology, the Health and Social Care Information Centre (HSCIC) and the AOMRC initiated a pilot project to develop a number of SNOMED CT subsets for outpatient data recording in a few volunteer specialties. There was at the time an imperative from the Department of Health to determine the identity, location and needs of disabled children and young people[15] (CYP) to inform appropriate commissioning arrangements. Therefore, disability, community child health and general paediatrics volunteered.

Paediatricians worked together with therapists from the British Academy of Childhood Disability, parents from the National Network of Parent Carer Forums and Terminologists from the HSCIC (formerly Connecting for Health). Broad concepts were developed for each area and then refined to remove duplications and resolve different nuances of meaning from the various perspectives to ensure relevance in practice across all the service settings.

The subset was designed to embrace the different stages of the journey, from initial presentation when concepts needed to be broad through to specific terms that could accurately capture the detail resulting from a period of assessment, thought, investigation and intervention. The scope of the design went beyond merely recording health conditions, but also included body structure, function, activities, participation and personal and environmental factors. This multifaceted approach allows for comprehensive data capture at each stage of the journey so that the holistic needs of the child or young person and their families can be accurately recorded.

A number of outdated concepts were identified in the SNOMED CT vocabulary, and requests were submitted for these to be deleted. A number of new concepts were requested, with supporting evidence. A detailed glossary[16] was published to make explicit the exact meaning of each term with supporting evidence and links to further information. This has provided valuable clarification across agencies, including education, social care and the voluntary sectors. The glossary has also been cited in a Special Educational Needs tribunal, where clarity about the difference between a 'disability' and 'difficulty' was paramount to addressing the needs of a specific child. The clinical concepts have been published online and are available for anyone to use.[17] Because the subset is small, it is possible to use it with a rudimentary EPR or even to collect the data on paper.

The usability and value of the subset has been confirmed by a retrospective analysis of 8329 consultations with 1999 CYP in Sunderland paediatric disability clinics between June 2007 and May 2012. Prospective testing has been undertaken by 22 clinicians across five tertiary and six district disability services in 2013. The benefits of comprehensive data recording using the subset at the point of care include quality assurance, definition of workload, local service planning including development of business cases, providing information for commissioning and facilitating audit.

Evidence provided from this work has influenced the design of the new Children and Young People's Health Services Secondary Uses Dataset.[18] The introduction of SNOMED CT to the design allows for a greater breadth and granularity of data to be submitted, including the capture of the childhood disabilities data. The pilot sites have been able to produce data illustrating the many and complex diagnoses, issues and situations being experienced by children with a range of disabling conditions seen is a range of specialty, general and community clinics. Features in SNOMED CT such as the IS-A relationships (figure 1) remove the burden for recording higher-level codes to enable aggregation for national reporting. An additional advantage of using SNOMED CT is that it will also enable more detailed investigation of the data if new trends are observed in national data.

General paediatric terms cover only a small fraction of paediatrics and therefore it is imperative that other specialties within the college start to give this matter their urgent attention. The adult rheumatologists are keen to extend their subset into paediatrics; this would probably be a good model for most subspecialties to adopt so that there is consistency in the terms used to describe the same diseases in children and adults.

CONCLUSION
The collection and recording of clinical data is changing. In future, clinicians will be involved in collecting data at the doctor–patient interface. This represents both a challenge and a huge opportunity to collect clinically meaningful data to improve patient care. At last the concept of collect once and use many times is within reach. However, clinicians working through their professional bodies need to take responsibility for ensuring that the SNOMED CT terminology is fit for purpose in their specialty. Huge benefits have been realised by paediatric disability. Other specialties within paediatrics need to learn from this to ensure similar benefits across all children's services.

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