Collecting Clinical Information in Outpatients

A pilot study using SNOMED CT®

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Summary

Over the past four years there has been a concerted effort to understand the potential benefits and implications of implementing SNOMED CT[1](**S**ystematized **No**menclature of **Med**icine **C**linical **T**erms) in secondary and tertiary care. A pilot project involving eight distinct specialties has demonstrated that there are benefits for specialists to work with clinical terminologists to ensure that the terminology reflects best current practice and to ensure clinical ownership of the terms within defined speciality subsets. One specialty has been able to gather sufficient clinical data in SNOMED CT to demonstrate benefits in terms of subsequent data analysis and acquisition of knowledge beneficial to the commissioning of the specialty.

The project has demonstrated a requirement for co-ordinated clinical involvement in the on-going development and support of SNOMED CT overseen by the Royal Colleges and specialty groups within them. The next steps involve further subset development and testing by specialties and trusts. This should include the development and analysis of quality indicators predicated upon clinician recorded data using SNOMED CT.

Within the project there has also been some interaction with groups that engage with patients and carers. Early indications are that there will also be benefits to patients and carers from the consistency and visibility achieved through developing and publishing specialty subsets, especially when they can view their patient record.

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[1] SNOMED® and SNOMED CT® are registered trademarks of the IHTSDO® (www.ihtsdo.org)

Background

In 2011 a joint report was published by the Academy of Medical Royal Colleges (AoMRC) and the NHS Information Centre entitled 'Hospital Episode Statistics (HES): Improving the quality and value of hospital data[1]'. In considering its recommendations, which included clinician-led data recording using Systematized Nomenclature of Medicine – Clinical Terms (SNOMEDCT) and collection of clinical data in outpatients, it noted that the use of SNOMEDCT was a key facilitator and was in line with the recommendation from a report by the Audit Commission in 2002[2].
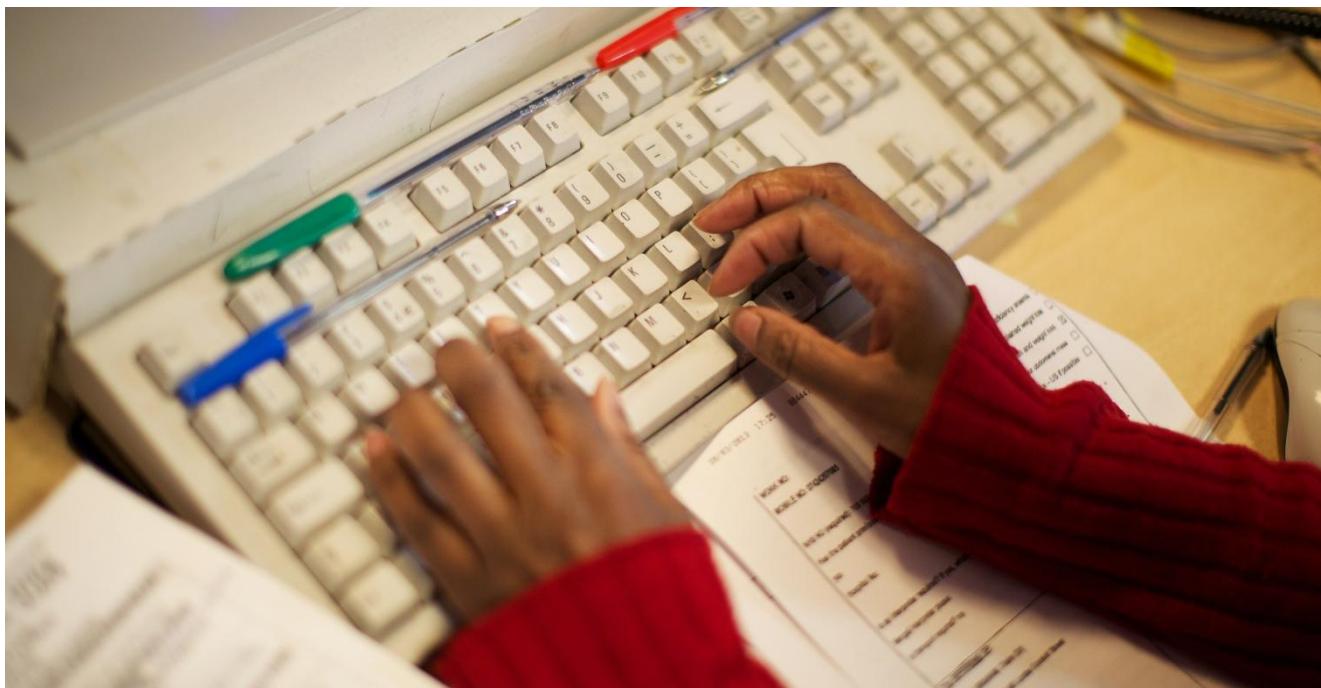
Following the publication of the AoMRC report a national survey of consultants was undertaken[3] which demonstrated that clinicians viewed "extraction of data from unstructured notes and lack of clinical validation" as the two most significant issues affecting the value of HES data for clinical use. Lack of clinical data from outpatients was also regarded as a significant problem.

In September 2011 a workshop was undertaken with representatives from the Royal Colleges, NHS Connecting for Health Terminologists, Clinical Coders, Commissioners, Quality Observatories and NHS Information Centre to explore in detail the advantages and practicalities of taking forward SNOMEDCT for use in outpatients.

A number of potential benefits were identified:

- The design and monitoring of care pathways. Also the joining together of inpatient, outpatient and potentially primary care data will help to formulate an understanding of how patients flow through the whole system. Linkage to other databases such as Choose and Book could potentially enhance and greatly assist with this aspiration.

- Development of Payment by Results (PbR) tariffs for outpatient activity and procedures so that commissioning and funding could better reflect the complexity of activity undertaken in outpatients. This would provide commissioners with a better understanding of the importance of outpatient activity and patient pathways which would lead to better resource allocation and service provision. This would benefit patients because outpatient work on patients with complex needs would be recognised and properly funded leading to service improvement. Efficiency savings may follow because currently there is a large financial disincentive to undertaking costly work in outpatients, leading to the possibility of unnecessary admissions or day cases.

- Epidemiological studies including the prevalence of chronic disease and the measurement of disease progression including the development of complications. This increased information about chronic disease and the burden for patients and the NHS may provide evidence that's leads to the development of new government health policy and support the development of vigorous disease prevention campaigns.

- Improve efficiency through monitoring referrals to identify and manage the reasons for inappropriate referrals. An examination of the circumstances leading to non-attendance and rapid feedback to general practice, may lead to the development of strategies to improve this. An admission avoidance program would also benefit from this data.

- Provide GPs with detailed information about clinic caseloads, waiting times for specific conditions and outcomes to improve the targeting of referrals to the best and most appropriate provider.

- Benchmarking and audit of outpatient services/clinicians to support efficiency, quality, clinical governance and patient choice. This may include outcomes of inpatient procedures such as surgical complications presenting at follow up. Benchmarking interventions including prescribing (by data linkage) by diagnosis and outcomes in particular also has the potential to create efficiency gains.

- Improve patient care, through the provision of comparative performance and outcome data to clinicians. This data will also provide clinicians with evidence for appraisal and re-validation with the potential to lead to improvement in performance. The scope of PROMs would also be increased through linkage to a new outpatient HES.
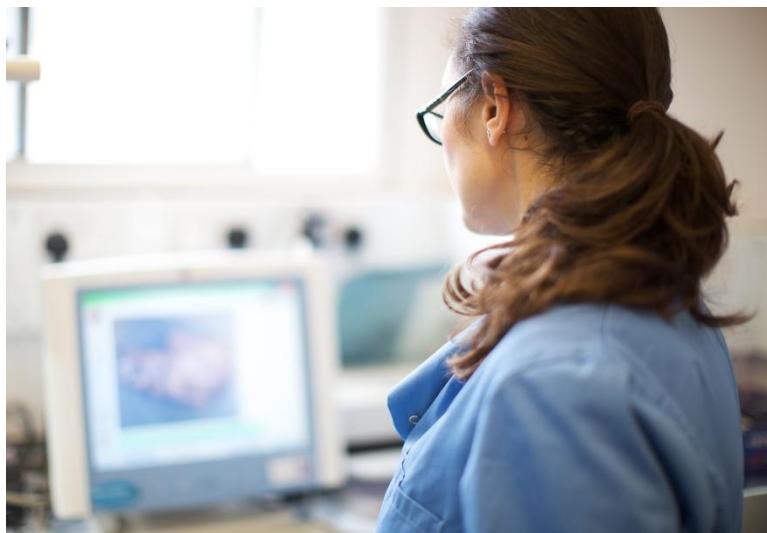
- Clinician involvement in the collection of this data would undoubtedly lead to improvements in coding, structured records and communication with general practice.

- Improvements to inpatient data; as success in outpatients will inevitably lead to clinicians to push for these to be adopted in the more complex environment of inpatient care.

The outcome of this workshop included the following next steps:

1. Health Informatics Unit (HUI) and the Department of Health Informatics Directorate (DHID) are working to develop data standards for the structured recording of clinical content for outpatients[4]. The primary purpose is to feed the clinic letter and provide an accurate clinical record for the on-going management of the patient. The data for secondary use must be a subset that can be extracted from this record.

2. Work with the Royal Colleges, clinical coders and clinical terminology experts to develop SNOMED subsets to ensure that all of the common conditions have agreed definition within the speciality, appropriate mapping to ICD-10/OPCS[2] and easy accessibility.

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[2] ICD-10: The International Classification of Diseases from the WHO; OPCS: The Classification of Interventions and Procedures

The Pilot Project; a Chronology

Following the workshop the AoMRC was asked to help to identify 10 specialities who would volunteer to be part of a pilot project to develop and test a subset of 100 commonly used terms to cover about 80% of outpatient diagnoses in their specialty. It was paramount that each volunteer had the formal agreement of their professional or speciality body so that the resulting terms and subsets when developed would become a national professional standard.

At the same time the National Casemix Office produced a framework document entitled SNOMED CT coded Diagnosis in Outpatients – Pilot Study. The stated aims of the project were:

- to improve data quality to support clinical audit

- to improve awareness and adoption of SNOMED CT.

The first workshop took place on 6th December 2013 at the Royal College of Paediatrics and Child Health headquarters, with representation from 11 different specialities. The workshop was extremely well attended and significant interest was shown on the day. An overview of the project, national context and vision for the future were given followed by training on SNOMEDCT and the use of an online term selection tool.

There was a lively discussion about whether the subsets should include symptoms as well as diagnosis. Although not fully resolved the majority were of the view that in real life patients can only be described by their symptoms until a diagnosis is reached and so a pragmatic approach was favoured that included both when relevant.

Armed with training, tools and support from the UK Terminology Centre (UKTC) the specialities agreed to develop their lists of terms. The majority of clinicians wanted to be brought back together to discuss the outcomes in 6 – 12 months.

In February 2013 there was a formal review of the progress made. At this stage the following specialities were actively working on developing their subsets:

- paediatric disability, community paediatrics and general paediatrics (Amalgamated 3 separate projects)

- gastro-enterology

- ophthalmology

- orthopaedics (Foot and Ankle)

- renal

- urology

- rheumatology

- respiratory

All of these specialties were still active when the follow up workshop was held on 25th June 2013 at the AoMRC headquarters. .

In addition to reporting on progress the workshop aimed to update the national context with keynote talks by representatives from NHS England. There was also a helpful terminology perspective from the UK Terminology Centre in the Health and Social Care Information Centre (HSCIC) as summarised below:

- The subsets should have a clearly defined scope of use which was to support data recording for clinical care, not statistical requirements

- The designation of concepts in the subset should be the 100 most frequently encountered diagnoses, not all diagnoses encountered grouped into 100 'categories'

- The level of detail captured will impact any secondary uses derived from the SNOMED CT data

- Requests for change/new content can be submitted to the UKTC at http://systems.hscic.gov.uk/data/uktc/snomed/change

- It is important for the longevity of the subsets that ownership is persistent (permanent), the intention being that ownership was by the professional body

- The contributions of a terminologist, in addition to the domain experts has proven invaluable

- It is often desirable to have representation from those that interact with the domain involved at some stage (as well as those that are domain experts)

It was evident from the sub-speciality presentations that different specialities had taken different approaches to the challenge of coming up with approximately 100 codes.

The paediatric subspecialties amalgamated as in discussions they discovered there was significant overlap and commonality in requirement. They felt it would be constructive to gain agreement between them and as a group it was realistic to have circa 300 terms. In paediatric disability, the project has allowed the development of terms for functional as well as clinical diagnosis, also family reported issues and technological dependencies, which is of the utmost importance for deriving the burden of care. Parent-carers and other health professionals had been involved in developing the subset in order to provide the widest possible application. A glossary of the terms with their agreed meaning was also published online.

Rheumatology initially focused on inflammatory arthritis and started with the peer group to agree how that area should be recorded, including the hierarchy and the appropriate level of granularity. SNOMED CT was searched for the required terms. This resulted in one of three outcomes: identifying existing concepts that were fit for purpose, finding gaps and generating requests for new concepts or finding the concept but requesting changes to the name, synonyms or position in the hierarchy.


Orthopaedics kept the focus very narrow to just the foot and ankle. This project focused on diagnoses that came through elective procedures. There is an imperative in surgery to record procedures accurately for PbR, so they would have preferred to have started with procedures and then work back to diagnosis. It was recognised that there is a huge overlap between rheumatology and orthopaedics so some joint working has been initiated as both specialties now seek to expand their subsets.

Gastro-enterology had an existing database in use at one hospital which had been routinely standardising the way they recorded diagnoses over the last 10 years or so. An extract was taken from this database of the diagnosis terms. The professional body also had a list of the clinical terms that all junior doctors should know and this list was checked with the database extract to ensure all of these were in the subset. In addition it was agreed that not just diagnosis was required but also the stage. This meant the subset contained high level terms for recording on initial contact with the patient, but then additional terms could be added to the record as the management of the patient progressed.

Renal and ophthalmology had existing subsets and these were reviewed following the findings discussed in the workshops. The ophthalmology subset is in active use in a number of hospitals.

Because the number of terms had been restricted to make the project manageable, there was a tendency to restrict the choice to high level terms so that as many patients as possible were covered by the subset. This was not ideal for the pilot as the development in SNOMEDCT is intended to provide clinicians with the granularity they require for quality improvement and audit. This granularity is also required to enable accurate mapping to the ICD-10 classification.

Following the workshop the subsets which had been developed were published online. Orthopaedics planned to use their subset at the Royal National Orthopaedic Hospital. The paediatric subset was to be used nationally for paediatric disability. An interface was developed in Sunderland specifically to capture these terms, other trusts made their own arrangement even using paper collection where necessary. There was also an agreement to explore the possibility of asking trusts with SNOMEDCT enabled electronic patients records (EPR) to use and test subsets where clinicians in the relevant speciality were interested. This has been explored but unfortunately the majority of trusts with an SNOMED CT enable EPR are not able to separate out the subsets in a fully searchable format.
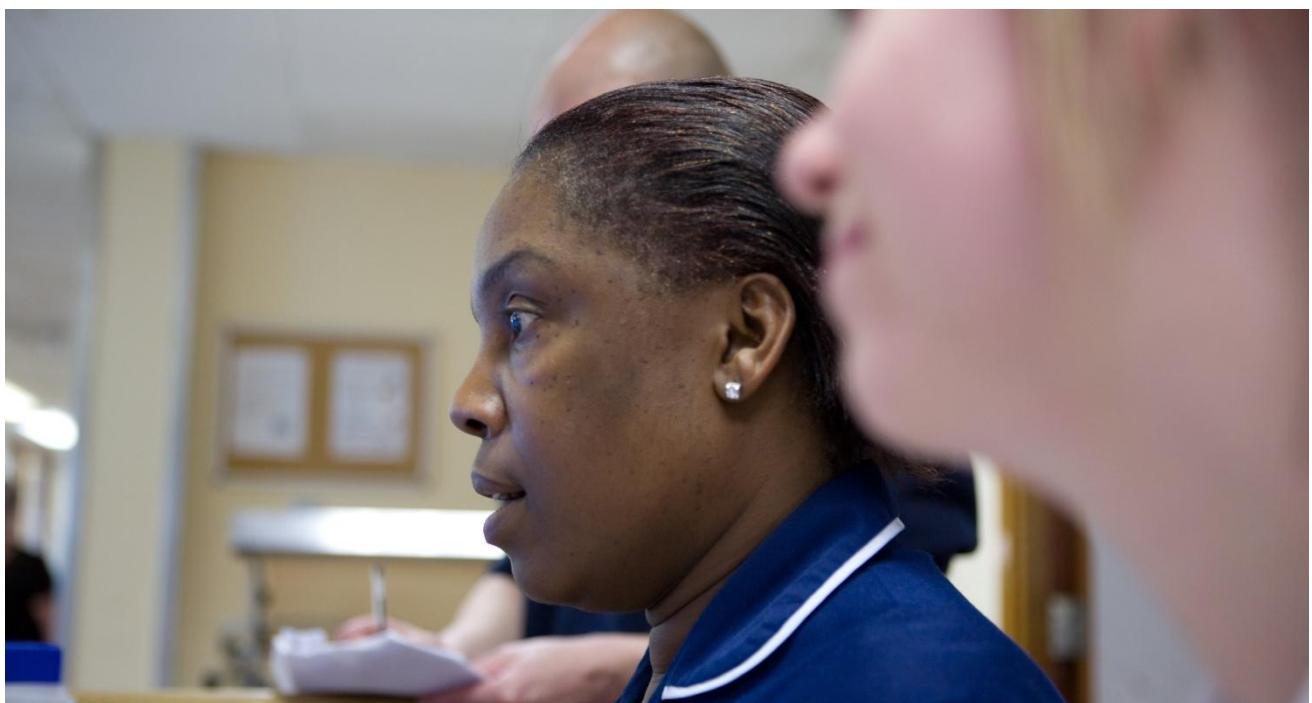
The final workshop took place on 7th October 2014 in London. The objective was to learn as much as possible from the experience of those developing subsets for their specialty and to promote testing in volunteer trusts. Most of the trusts that had shown an interest in testing were unable to provide adequate feedback due to time constraints and competing priorities. It has since become evident that trust involvement is going to require a funding stream and is therefore outside the scope of the original project. Nevertheless the meeting provided an opportunity for review of the process by those involved and for experiences to be shared with many of the specialties planning to use or further develop their subsets.

Conclusions

The pilot project has highlighted a number of key points:

- Terminology must continually develop to accommodate advances in healthcare such as genomics (use of SNOMED CT for phenotype data) stratified medicines and rare diseases. As such, subsets also need to be maintained.

- The same diagnosis can be referred to in a very different way between different clinical specialities, for example rheumatologists may refer to a condition differently to an orthopaedic surgeon. Agreement and liaison across the relevant specialities will be required for some of the terms. It is also important to recognise that different specialties require a different level of granularity for the same condition – this is accommodated within SNOMED CT but does emphasise the desirability of speciality based subsets.

- Synonyms are a powerful mechanism but need cleaning up in some areas. Some exist in the terminology that should now never be used for data entry; it should be remembered that they may need to stay in the terminology for historical reports. Medical knowledge has moved on and it is now recognised these terms do not represent a proper understanding of pathophysiology.

- A number of specialties have national registers, and some of these may already have the diagnosis described. These will be a good starting point for cross checking with the SNOMED CT terminology.

- Each speciality requires an expert clinical reference group (ECRG), sanctioned by the relevant professional body, so that all developments/changes to the SNOMED CT subset represent a national standard and adherence to sound principals of data recording can be encouraged across the specialty. It should be noted that SNOMED CT is international and the ECRG can monitor terms that come into the international content of the terminology and determine which are included in their speciality subset.

- The role of a professional clinical terminologist is key in supporting the ECRGs. Most specialities would not have succeeded without considerable input from the terminologist who worked closely with them.

- It is important that the ECRG leads a discussion about the level of detail (granularity) that should be encapsulated in a clinical term (unstructured text can be used to capture everything additional which is relevant to the care of the individual patient). This is a crucial point because too little detail will severely hamper future analysis and too much detail will render the system unwieldy and possibly unworkable at the patient interface.

- The national subset should be a superset of what is required by the profession as a whole. To claim the subset represents everything that speciality will need is an impossible task.

- For some specialties it is desirable/necessary to have a glossary with definitions to support consistent recording across the profession.

- Subsets should be reviewed by the ECRG from a clinical perspective on an annual basis unless there is a particular initiative or problem in a clinical area requiring urgent review. Any changes must be sanctioned by the ECRG.

- Disease severity is very important to some specialties, but still largely unresolved as how to manage this in current EPR systems. Clearly defined disease specific severity, such as grading systems according to set criterion can be incorporated into SNOMED CT, but require this information to qualify that already recorded; not all EPR systems currently provide this ability. Mild, moderate and severe are also available within SNOMED CT but are probably not useful because the terms will not be used consistently unless there is an agreed definition for the disease entity in which they are being used.

- Clinicians require data analysis to test hypotheses and to monitor the emergence of trends. They also need to undertake analysis for clinical audit, patient safety and quality improvement. Data must be recorded in a standardised way as provided by SNOMED CT for these analyses to take place. It is therefore also important for clinicians to be able to access and analyse their data with tooling that takes advantage of the features of SNOMED CT. These tools are not currently readily available to clinicians, neither is access to their data. Tools do exist but this is still a developing market. Acting on a sound interpretation of the data will lead to better care and better service delivery.

- Clinical champions are needed to advocate for the use and the benefits of SNOMED CT and to start illustrating real examples of what is possible.

- It is important to get Information Technology staff/Chief Information Officers/Chief Clinical Information officers on board.

Outcomes from the pilot:

1. Eight diagnosis subsets for outpatients have been published[5], further subsets have also been produced following on-going interaction with the UK Terminology Centre.
2. Two peer reviewed publications[6;7] in medical journals with at least four others submitted[8-10].
3. Better visibility of patient population, volumes and complexity of care (due to multiple conditions) in paediatric disability. This has led to resource and service changes.
4. The national dataset for Children and Young People's health services which is soon to be implemented has been modified to include the disability subset and SNOMED CT terming in general.
5. The Royal Colleges of Paediatrics and Child Health are engaged with further developments in SNOMED CT.
6. Continuing interest from NHS England has ensured that SNOMED CT is used for data collection in the genomics project.
7. Many of the clinicians involved in the pilot project will be clinical champions for future developments.

Next steps

The current subsets have been reviewed by clinicians and determined appropriate for data entry in the record. A small number of the subsets have been tested and some are used in live applications. The national strategy to reduce the burden of duplicate data entry into additional tools for audit and secondary uses can be achieved by extracting structured data from the EPR; this aspect requires further work. Initial discussions are underway with some of the national audits.

Future priorities highlighted by clinicians working on the project include:

- A plan of action to increase the visibility of SNOMED CT amongst clinicians. The excellent online training tools need to be widely promoted to this end[11,12].

- Visibility of the set of agreed terms for a particular clinical speciality is valuable for speeding up data recording by clinicians. This needs to be more widely publicised and extended to other clinical specialities.

- All clinical specialities should start to use and include the relevant subset content in pre-registration training to develop familiarity with the appropriate SNOMED CT terms. Discussions are on-going with a number of the professional bodies to take this pilot work further.

- Clinicians need to have improved have access to their own clinical data for audit, quality improvement and clinical led outcomes analysis; this includes the appropriate tools to support such analysis.

- Improved search facilities to enable selection of the correct SNOMED Clinical Terms, with data entry approaches that are fast and efficient for clinical use.

It was also felt that long standing processes developed when paper records were prevalent need to be reviewed, and that benefits from structured content should be felt by early adopters of electronic records in a timely manner rather than progressing at the rate of slowest. Without this, the momentum to adopt structured content in electronic records could lose momentum.

Reference list

(1) Spencer, S A. Hospital Episode Statisitics (HES): Improving the quality and value of hospital data: A discussion document. 2011; http://www.aomrc.org.uk/doc_download/9379-hospital-episode-statistics-improving-the-quality-and-value-of-hospital-data-discussion-document

(2) Audit Commission. data remember improving the quality of patient-based information in the NHS. Audit Commission Publications; 2002; http://archive.audit-commission.gov.uk/auditcommission/sitecollectiondocuments/AuditCommissionReports/NationalStudies/dataremember.pdf (3) Spencer SA, Davies MP. Hospital episode statistics: improving the quality and value of hospital data: a national internet e-survey of hospital consultants. *BMJ Open* 2012; 2(6).

(4) Health Informatics Unit RCP. Standards for the clinical structure and content of patient records. 1-7-2013; https://www.rcplondon.ac.uk/sites/default/files/standards-for-the-clinical-structure-and-content-of-patient-records.pdf

(5) SNOMEDCT Subset Browser. 2014 [cited 2014 Dec. 16]; Available from: URL:http://www.diseasesdatabase.com/snomed/snomed_subset_browser.asp?dblSubsetID=56931000000136

(6) Gaywood I, Pande I. Preparing for electronic health records - Standardizing Terminology. *Rheumatology* 2014; doi:10.1093/rheumatology/keu383.

(7) Gaywood I, Pande I, Cheetham E. Standardizing Terminology for Musculoskeletal Disorders. *Rheumatology* 2014; 53(Suppl 1).

(8) Horridge KA, Williams J, Whilinghum G, Busk M. Data Matters for Disabled Children and Young People: Prospective Pilots of Routine Data Capture by Paediatricians in a Range of Outpatient Clinic Settings. *Planned for* 2015.

(9) Horridge KA, Harvey C. Data Matters for Disabled Children and Young People: retrospective analysis of a district paediatric disability clinic population using a defined set of terminologies. *Planned for* 2015.

(10) Spencer A, Horridge K, Downs D. **Empowering clinical data collection at the point of care**. *Arch Dis Child* 2015.

(11) IHTSDO guidance and documentation: http://www.ihtsdo.org/snomed-ct/learn-more

(12) UK Terminology learning resources: http://systems.hscic.gov.uk/data/uktc/training