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Miscellaneous

Creating a SNOMED CT reference set for common endocrine disorders based on routine clinic correspondence

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Abstract

Background: Routine clinical coding of clinical outcomes in outpatient consultations still lags behind the coding of episodes of inpatient care. Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) offers an opportunity for standardised coding of key clinical information. Identifying the most commonly required SNOMED terms and grouping these into a reference set will aid future adoption in routine clinical care.

Objective: To create a common endocrinology reference set to standardise the coding for outcomes of outpatient endocrine consultations, using a semi-automated extraction of information from existing clinical correspondence.

Methods: Retrospective review of data from an adult tertiary outpatient endocrine clinic between 2018 and 2019. A total of 1870 patients from postcodes within two regional areas of NHS Grampian (Aberdeen City and Aberdeenshire) attended the clinic. Following consultation, an automated script extracted each problem statement which was manually coded using the 'disorder' concepts from SNOMED CT (UK edition).

Results: The review identified 298 relevant endocrine diagnoses, 99 findings and 142 procedures. There were a total of 88 (29.5%) commonly seen endocrine conditions (e.g., Graves' disease, anterior hypopituitarism and Addison's disease) and 210 (70.5%) less commonly seen endocrine conditions. Subsequently, consultant endocrinologists completed a survey regarding the common endocrine conditions; 28 conditions have 100% agreement, 25 have 90%-99% agreement, 31 have 50%-89% agreement and 4 have less than 59% agreement (which were excluded). Conclusion: Automated text parsing of structured endocrine correspondence allowed the creation of a SNOMED CT reference set for common endocrine disorders. This will facilitate funding and planning of service provision in endocrinology by allowing more accurate characterisation of the patient cohorts needing specialist endocrine care.

KEYWORDS

clinical problem lists, endocrinology, medical coding, ontology, outpatient consultation, pituitary, reference set, Refset, SNOMED CT, thyroid

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1 | INTRODUCTION

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Electronic patient records systems are currently routinely used for the recording of information about the management of endocrine disorders in both specialist and primary care settings. Though accounting for more than 8% of the global disease burden,¹ most healthcare services in the UK have not adopted a standardised coding system for endocrinology to help collate the extensive clinical information required to enable decision support, service planning, and quality improvement. By comparison, medical coding of inpatient endocrine admissions is routinely performed by clinical coders after the episode of care has been completed, using the 10th revision of the International Classification of Diseases Clinical Modification (ICD-10-CM). However, formal coding of diagnoses in outpatient endocrine practice is not carried out routinely within the specialist clinical practice including the NHS. There is a pressing need for contemporary clinical reference terminology that could promote the point-of-care recording of clinical information by providing a standardised representation of clinical disorders and incidents in electronic health records and other clinical information systems.

Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) has been designated as the recommended clinical reference terminology for use in clinical information systems globally.² The General Assembly of the International Health Terminology Standards Development Organisation (IHTSDO) owns and administrates the rights to SNOMED CT and consists of 23 member countries. Different countries have their respective editions of SNOMED CT. SNOMED CT is now recognised as the global standard for coding clinical information to benefit both individual patients, as well as populations. United Kingdom, being one of the founding members of SNOMED International, has their own "UK Edition" which consists of a total of approximately 380,000 medications and 350,000 clinical concepts. The "UK Edition" includes all international clinical concepts with an additional 88,000 (approximately) UK clinical concepts. In England, all NHS provider organisations were required to adopt SNOMED CT in the direct patient care process by 2020.³ The clinical reference terminology provided by SNOMED CT has been proven to be more extensive and reliable compared to classification systems.^{4,5} It acts as a structured clinical vocabulary that facilitates the sharing of information such as diagnosis, procedures and symptoms, consistently within and across different healthcare settings. This supports point-of-care clinical decision-making and reduces the risk of misinterpreting records across different healthcare settings.⁶ Figure 1 shows the hierarchies of SNOMED CT concepts and uses the example of acromegaly to illustrate relationships linked to other concepts.⁷

A SNOMED CT reference set is a specific subset of components like concepts, descriptions, or relationships relevant to a particular medical domain. It contains a set of coded clinical terms that represents information consistently utilised in a specific medical sector. A reference set enables the listing and utilisation of commonly used clinical terms and can enhance the quality of data recorded. This would potentially help in analysing ways to improve access, outcome, quality and management of clinical care.⁸ The reference set can be used to provide the list of diagnoses from pick lists during outpatient appointments in routine primary or secondary care clinics for endocrine problems. This facilitates a wide variety of clinical usage for case identification, audit, research, and service redesign to facilitate remote follow-up for appropriate clinical encounters.

In this report, a structured approach was developed to create a SNOMED CT reference set for routine clinical endocrinology-related concepts, such that it can support data entry in an outpatient clinic setting. A framework, developed by SNOMED International, was utilised which involves a multi-step approach for the creation of the reference set.⁹ The resultant reference set can be integrated into the Electronic Patient Records system to provide healthcare professionals with a standardised set of clinical terms for the coding of common endocrine disorders.

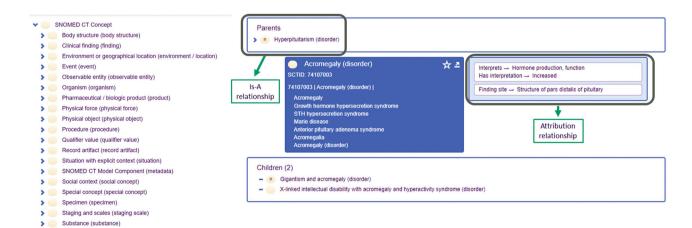


FIGURE 1 The different hierarchies of SNOMED CT, each concept has its unique descriptive term, a set of synonyms and a preferred term. 'Is-A relationship'—Acromegaly has one Is-A relationship; it is a hyperpituitarism disorder. 'Attribution relationship' is the association between two concepts—Acromegaly has three such attribution relationships.

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2 | METHODS

A retrospective review of data from an adult outpatient endocrine clinic database was performed. Data were collected from an adult, outpatient endocrine clinic based in a tertiary referral centre (Aberdeen, Scotland) with the aim of creating a reference set suitable for healthcare professionals to utilise in other outpatient clinic settings.

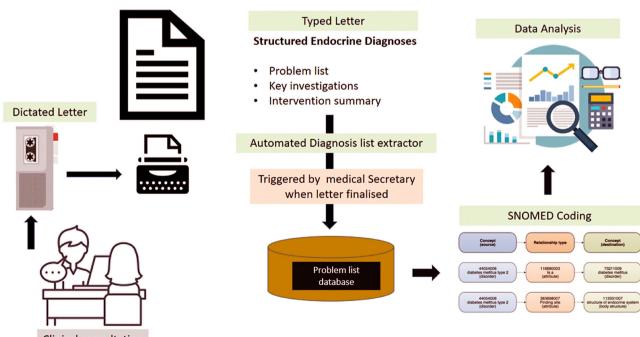
Patients aged 16 years or above that attended the Endocrine clinic from 1 January 2018 to 31 December 2019 and whose postal codes of residence were within the geographical area of Aberdeen City and Aberdeenshire were included. The total population size of these two areas was 489,030 and 489,880 in the years 2018 and 2019 respectively.¹⁰

Data collected from this tertiary care clinic includes all subspecialties of endocrinology with some exceptions. Reproductive endocrine, gender identity, thyroid nodules, thyroid cancer and thyroid disorders during pregnancy are not included in this study as they are managed in separate sub-speciality clinics. In addition, primary hypothyroidism is usually dealt with in the primary care setting and is rarely seen in secondary or tertiary care clinics. People with diabetes mellitus were not included as their care is managed in separate diabetes clinics within a separate clinical information system.

In this tertiary care clinic, all medical records of patients were reviewed by clinical endocrinologists, with the final endocrine diagnoses made by them. Clinical diagnoses were made after taking a history, carrying out physical examinations and reviewing relevant laboratory and radiological investigations. After each clinical consultation, which may be face-to-face or remote, a structured letter was created, containing a detailed problem list for each patient, including the key investigations, procedures, and interventions. Structured correspondence was adopted to provide more uniform output from clinic appointments and ensure key information was captured, despite clinics being conducted by different healthcare professionals. The selected terms and data captured for producing the reference set will consist of the categories, hierarchy, concept's term, unique code and the frequency of patients that were diagnosed with that particular endocrine disorder.

The SNOMED International framework was followed for reference set development.⁹ There are various types of reference set designs, and a simple reference set type was developed using concepts from the "UK Edition" through manual enumeration. Keywords related to endocrinology were automatically generated from the structured letter via the automated diagnosis list extractor (Figure 2). This includes presenting symptoms and signs, procedures carried out and final diagnoses.

All clinical information extracted was input into a database using Microsoft Excel 2007 software and was then manually coded (by the first author) into the 'disorder', 'procedure' and 'finding' concepts from SNOMED CT UK Edition v20220803. The list of terms generated was reviewed by the supervising author SP and a consensus was reached between the two authors regarding any disagreements on the problem statement and the SNOMED term by reviewing the SNOMED CT description of the term. The coded concepts were then classified according to broad classification categories from within ICD-10-CM, which are as follows: (1) thyroid gland and thyroid hormone disorders, (2) pituitary gland disorders, (3)



Clinical consultation

FIGURE 2 Process of data extraction, coding and analysis for the study.

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parathyroid and calcium metabolic disorders, (4) adrenal glands disorders, (5) gonadal disorders, and (6) disorders of other endocrine glands. All endocrine disorder concepts were then further categorised into *commonly seen* and *less commonly seen* in a UK tertiary outpatient endocrine clinic. This is based on the criteria where more than 5 cases seen in the clinic will be classified under commonly seen endocrine disorders, while 1–5 cases seen in the clinic will be classified under less commonly seen endocrine disorders.

A survey of 11 consultant endocrinologists, each with at least 7 years of specialist experience in endocrinology, was undertaken. The survey contained a list of endocrine disorder concepts and the clinicians then determined whether they agreed or disagreed that these were commonly seen endocrine disorders in a tertiary outpatient endocrine clinic setting. They were also allowed to select "unsure" and leave comments about the particular concept. Those concepts with >50% agreement remained within the commonly seen reference set, whereas the rest were excluded.

3 | RESULTS

A total of 1870 patients attended the outpatient endocrine clinic in ARI between 1 January 2018 and 31 December 2019. A total of 298 relevant endocrine disorder diagnosis concepts were derived from the patients that attended this clinic during these 2 years. There were also 99 findings, and 142 procedures derived. There were no duplicated concepts. After further categorising, there was a total of 88 (29.5%) commonly seen endocrine disorder concepts and 210 (70.5%) less commonly seen endocrine disorder concepts. A total of 5211 clinical encounters were captured from the structured clinical correspondence using an automated extraction algorithm implemented from Microsoft Visual Basic. Among them, 63% of the clinical encounters captured were from the commonly seen endocrine disorder list. Whereas 18% of clinical encounters captured were from the less commonly seen endocrine disorder list. The remaining 19% are clinical encounters that did not result in a definitive endocrine diagnosis.

Through the method described earlier, the commonly seen endocrine disorder concepts obtained were reviewed by experienced endocrinologist clinicians in a survey. Among these 88 concepts, 29 of them have 100% agreement, 34 of them have 80%–99% agreement, 21 of them have 50% to 79% agreement and 4 of them have less than 50% agreement. We excluded the four concepts that have less than 50% agreement. Every concept has its unique descriptive terms and associated identifiers code that include 6-to-18-digit codes. The final reference set was eventually generated, which consists of 84 commonly seen endocrine disorder concepts (see Supporting Information Appendices A and B).

According to the data set collected over the 2 years period, thyroid disorders were the most common reason for consultation, comprising 39.5% of patients who attended follow-up reviews at this clinic. This is followed by pituitary disorders, gonadal disorders, and adrenal disorders, which comprise 24.0%, 12.9% and 12.5%, respectively (Figure 3). A total of 657 patients had multiple endocrine disorders. Table 1 shows the gender and ratio in each category of endocrine disorder. Other than gonadal disorders, all the remaining categories show women are more likely to be diagnosed with endocrine disorders. Parathyroid disorders have the highest female-

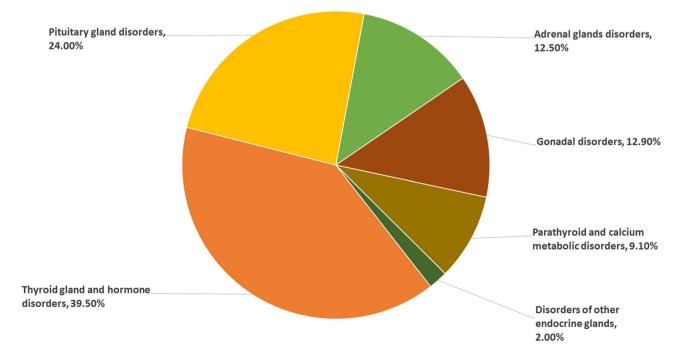


FIGURE 3 Pie chart showing the percentage (%) of each major endocrine disorder category reviewed in the clinic.

to-male ratio of 3.8:1. Table 2 shows the most common endocrine disorder in each category.

4 | DISCUSSION

The present study analysed the frequency of endocrine disorders seen in a population of almost half a million people. There were a total of 1870 patients seen with some patients having multiple common endocrine disorders. Among these patients, 298 endocrine disorder concepts were identified, of which 84 (28.2%) of them were deemed as commonly seen endocrine disorders based on our criteria. These concepts occupied 63% of the clinical encounters in this clinic.

A standardised medical coding system can facilitate the recording of routine medical correspondence and enable the collection of health data in a timely manner. It will improve understanding of conditions managed predominantly in outpatient settings, as well as facilitate adequate service provision and initiatives to improve the quality of care for endocrine disorders. Epidemiology studies including the measurement of disease progression and development of complications can be conducted more efficiently and in real time. Since most endocrine disorders are chronic diseases, the additional information will improve the understanding of these diseases and the burden for patients and healthcare systems. This can lead to the development of new government health policies and support the

TABLE 1	Gender distribution of each endocrine disorder
category.	

ICD 10 classification	Male	Female	Male:Female
Thyroid gland and hormone disorders	244	853	1:3.5
Pituitary gland disorders	295	370	1:1.3
Adrenal glands disorders	123	224	1:1.8
Gonadal disorders	205	152	1.3:1
Parathyroid and calcium metabolic disorders	53	201	1:3.8
Disorders of other endocrine glands	27	29	1:1

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development of prevention campaigns. Perhaps most importantly, this permits appropriate reimbursement in the many healthcare areas that rely on documentation of clinical activity to generate funding.

SNOMED CT is perceived as a valuable tool for use in clinical practice as it represents language used by clinicians.¹¹ Clinicians will be able to record patient information in an unambiguous and homogenous way. This ensures records can be shared and interpreted in a structured and secure form between different healthcare providers. Besides providing clear benefits to the patients, it can also reduce clinicians' administrative burden by allowing the reuse of appropriate data, enhancing the effectiveness of healthcare system evaluation, and ensuring a unified language across multiple healthcare IT systems. Any healthcare system that relies on clinical activity to generate funding relies on an accurate record of the complexity of patients seen along with any investigations and/or treatment instigated.

Our well-defined population study provides an up-to-date prevalence of endocrine disorders using the SNOMED CT coding. We adopted a pragmatic way of creating a reference set containing only commonly seen endocrine disorders, instead of an exhaustive reference set that contains all possible endocrine disorders diagnoses. Other countries utilising SNOMED CT can adjust this reference set to match the pattern of disease seen in their geographical area; the reference set provided can provide a useful starting point. In addition, using the different hierarchies of SNOMED CT coding (e.g., 'findings', 'procedures' and 'diagnoses') allows better organisation of collected data. This will help enhance the quality of audits and service improvement projects by improving efficiency and patient choice. This could also help to identify service and training demands for the various endocrine disorders in tertiary outpatient clinics in any part of the world. For instance, the greatest proportion of the clinic's workload was related to hyperthyroidism, with Graves' disease being the most seen endocrine disorder among all. Clinics can then allocate focused teaching and training in these more common disease areas. This will improve patient care and the quality of training in endocrinology.

The reference set was used for an initial service evaluation of patients attending the outpatient clinic to demonstrate the usefulness of machine-readable coding of clinical encounters. We were able to capture data about the clinic population allowing

TABLE 2 Frequency and proportion of the major endocrine disorders in the study.

ICD 10 classification	Most commonly seen endocrine disorder of each category	Frequency (n)	Percentage (%)
Thyroid gland and hormone disorders	Graves' disease	319	17.1
Pituitary gland disorders	Anterior pituitary hormone deficiency	108	5.8
Adrenal glands disorders	Addison's disease	64	3.4
Gonadal disorders	Hypogonadotropic hypogonadism	72	3.9
Parathyroid and calcium metabolic disorders	Primary hyperparathyroidism	108	5.8
Disorders of other endocrine glands	Malignant neuroendocrine tumour	14	0.7

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ascertainment of the prevalence rate of various endocrine conditions. The results obtained are in sync with other epidemiology studies conducted in other countries. However, the data from this service evaluation will not be available in this report.

Many articles published globally portray the benefits of having implemented SNOMED CT in their healthcare systems.^{5,12–16} In the UK, various case studies from NHS Rotherham, NHS Sunderland and NHS Wales have demonstrated benefits of SNOMED CT.¹²⁻¹⁴ Similarly, a pilot project involving eight distinct specialities, overseen by the Royal Colleges and their speciality groups within them, demonstrated the benefits of SNOMED CT brought within each defined speciality subset.¹⁵ An article published in Rochester, Minnesota, has also shown that SNOMED CT can represent most of the terms used commonly in medical problem lists at up to 92.3%.⁵ Another study involving 13 different healthcare organisations across eight countries, examined the benefits of SNOMED CT implementation through a series of interviews and surveys.¹⁶ Other countries, using a variety of methods, have created different versions of reference sets. In Australia, a software platform (Snapper) facilitated the mapping of existing clinical terms to SNOMED CT to create a national emergency department data reference set.¹⁷ A Canadian study discussed a reference set created for respiratory disorders in newborn infants based on evaluation by three independent neonatologists.¹⁸

When comparing the different methodologies used, adopting an existing reference set or using an automated strategy is certainly faster. However, it does not necessarily achieve the best results as there will be some variability between different medical specialities and between different countries. The current study's methodology is pragmatic as the results were based on the actual number and details of patients seen in a tertiary outpatient clinic. The list was manually reviewed by domain experts, selecting the most appropriate contextually and clinically relevant SNOMED CT endocrine disorder concepts to be included in this reference set. The advantage of involving domain experts is that they recognise the relevant terms within the context and are able to identify terms that are irrelevant and redundant so that they could be excluded. This reference set would therefore be more accurate and applicable for use by other outpatient clinics. A Kenyan study recording AIDS-defining illnesses adopted a similar approach to ours in creating a reference set.¹⁹

There are some limitations to this study. Although the data collected from this tertiary care clinic included most subspecialties of endocrinology, there were some exceptions (detailed in the methods). With further time these areas could be included. Although findings and procedures were included in the data extraction and were also coded accordingly, they were not included in the final reference set. This is because they had a very wide scope that could overlap with other disease areas. Furthermore, the procedures, medications and treatment plans used to manage the patients in this clinic are based on local guidelines. Different healthcare providers may have alternative approaches to managing patients with similar endocrine disorders. Unlike a diagnosis reference set, creating a reference set that includes findings and procedures might be less useful as it might not be directly applicable to other healthcare systems or even other

NHS healthcare providers. Nonetheless, we have compiled a list of these, should these be of interest to the national coding teams.

To establish a formal diagnosis in endocrinology, patients may require to undergo various lengthy investigations over a period of time. At times, the diagnosis is even derived from the response to management based on a series of timely investigation results. This limitation may result in the under-representation of some endocrine disorders. In some cases, patients might not even receive a formal diagnosis within this set time frame of data collection. SNOMED coding of presenting symptoms and endocrine investigations including results of any dynamic function tests before formal diagnosis will be also useful information for the service and should be considered in future coding projects.

The data collected is related to patients attending this tertiary outpatient endocrine clinic within the 2 years data collection period. Since this is a regional clinic, the information collected would be limited to the geographical region. The disease prevalence may vary in other areas and as such, this reference set might not be extensive enough to be used by other outpatient endocrine clinics in other parts of the UK or internationally. Moreover, there could be patients who were already diagnosed with endocrine disorders but were not reviewed during this 2-year period as their conditions were stable. Those who failed to attend the scheduled clinic for various reasons or have migrated away would also be missed out on this study. To mitigate this, domain experts were able to identify and include endocrine disorders that were missed in the initial reference set. This reference set is a 'starter subset', which contains an adequate list of common endocrine disorders that could serve as an initial reference set that can be further revised by other clinicians, adding or removing diagnosis concepts in accordance with the different clinical settings and preferences.

5 | CONCLUSION

We have described a structured approach to deriving a SNOMED CT reference set for common endocrine disorders. This does not aim to be an exhaustive list of endocrine disorders but should be adequate for coding most clinical encounters in an outpatient setting for endocrinology. This reference set will be a useful tool for clinicians to use within structured clinical correspondence, as well as enabling the recording of machine-readable data within clinical information systems. This reference set can be made available to interested clinicians on request. Future work needs to be done to expand and evaluate the effectiveness of this reference set along with deriving reference sets for clinical features, investigations, and procedures.

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CONFLICT OF INTEREST STATEMENT

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared except for the reference set made.

ETHICS STATEMENTS

Patients' consent for publication is not required. This service evaluation uses an anonymised data set with study numbers only and without any patient-identifiable data. It was agreed by the North of Scotland Research Ethics Committee at the local health board that ethical approval was not required.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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