Chronic Paediatric Comorbidity Codelists

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The problem

Identification of children and young people (CYP) with chronic paediatric conditions in routinely collected healthcare data for research has been limited to secondary care ICD-10 codelists.[1] However, many chronic paediatric conditions are managed in primary care, and omission of these will fail to characterise the breadth of comorbidity experienced by CYP. Primary care codelists, using SNOMED and Read version 2 (Read v2) coding systems, exist for adult chronic conditions but cannot be applied to the paediatric population as conditions are often very different. For example, adult chronic conditions codelists often focus on pathologies such as ischaemic heart disease or chronic obstructive pulmonary disease which are less applicable for a paediatric population, whilst key chronic conditions in paediatrics (e.g. congenital and chromosomal conditions) are not represented. A harmonised codelist of chronic paediatric conditions is needed to link primary and secondary care analyses across the UK to understand the true prevalence and impact of these conditions.

Methods

As part of a project examining healthcare use in CYP following SARS-CoV-2 infection (SLICK)[2] we produced a set of harmonised primary and secondary care codelists for chronic paediatric conditions spanning three coding systems commonly used in the UK (ICD-10, SNOMED and Read v2).

Chronic paediatric conditions were defined using the Hardelid 2014 definition: [1]

"Any health problem requiring medical follow-up for more than 12 months in 50% or more of cases.

Medical follow-up is defined as:

- Hospital admission OR
- Specialist follow-up through outpatient department visits OR
- Use of support services such as physiotherapy or speech and language therapy."

We used Hardelid et al.'s well-established ICD-10 chronic paediatric conditions codelist[1] as a starting point. The ICD-10 list of conditions was initially screened by two paediatricians (OVS and TCW), with disagreements resolved by a third (LP). Conditions considered acute were removed.

In addition, for our current study, the following groups of conditions were also broadly excluded:

- Substance abuse (unclear if acute or chronic)
- Self-harm (examined elsewhere in our study)
- Drug-induced conditions (unclear if acute or chronic)
- Infections (except HIV / hepatitis B / hepatitis C and congenital infections (syphilis / toxoplasmosis / rubella / herpes simplex virus and cytomegalovirus)
- Acute infections unless chronic sequalae specifically stated (e.g. hydrocephalus secondary to meningitis)
- Very broad categories which could represent acute findings (e.g. neutropenia, cardiomegaly)
- Skeletal injuries / amputations / abnormalities (not relevant to current study)
- Skin / ear / eye disorders (in the interest of time for this study)

We included:

- Disorders associated with radiotherapy (presumed chronic)
- Alcohol induced disorders (except acute intoxication)
- Functional disorders (as significant medical attention often sought)

Integration of existing codelists

We used existing published codelists for Read v2 and SNOMED codes for asthma, diabetes, cancer severe mental illness and autism (see below).

Mapping of ICD-10 lists to SNOMED and Read v2 codes

For the remaining conditions, we created new codelists using the CALIBER R package to map the refined ICD-10 codelist to SNOMED and Read v2 codes[3] using the Technology Reference Update Distribution NHS Data Migration tables for reference. These SNOMED and Read v2 codelists were screened by one of three paediatricians (LP, TCW and LKF) and further reviewed by sub-specialists (Chronic Paediatric Conditions Committee – members detailed below). Disagreements were resolved by a fourth paediatrician (OVS).

Whilst ICD-10 is diagnosis-based, both SNOMED and Read v2 coding systems contain other categories including "findings" which some ICD-10 diagnoses can also map to. In order to keep our codelists diagnosis-based, we excluded all findings unless they described the presence of a device / stoma / prosthesis or transplant. Personal or family histories of a diagnosis were also excluded. Where published codelists were used, these were screened and findings removed for consistency before use.

Points on each comorbidity subgroup

Asthma

- ICD-10 asthma diagnoses as per Hardelid list.
- Read v2 asthma codelist: https://phenotypes.healthdatagateway.org/phenotypes/PH680/version/1360/detail/
- SNOMED asthma codelist: https://www.opencodelists.org/codelist/primis-covid19-vacc-uptake/ast/v.1.5.3/#full-list

Cystic Fibrosis

- Read v2 cystic fibrosis codelist: https://phenotypes.healthdatagateway.org/phenotypes/PH14/version/28/detail/
- ICD-10 cystic fibrosis diagnoses as per Hardelid list then mapped through CALIBER to produce SNOMED codelist.

Other respiratory

- Excludes asthma and cystic fibrosis (covered in separate codelists).
- Includes other chronic paediatric respiratory conditions (e.g. bronchiectasis, interstitial lung disease and respiratory conditions due to external agents), chronic respiratory disease of the perinatal period, presence of a tracheostomy or dependence on respiratory support / oxygen.
- Includes congenital respiratory conditions (nose, palate, larynx, trachea and lungs).

Cardiovascular

- Excludes diseases of the lymphatics / capillaries / peripheral vascular disease and embolisms / thromboses of veins / arteries.
- Includes congenital heart disease, acquired cardiac disease (e.g. rheumatic heart disease, cardiomyopathy, hypertension and ischaemic heart disease), arrhythmias and presence of cardiac and vascular implants and grafts.

Epilepsy

- Excludes febrile seizures.
- Includes epilepsy syndromes.
- As approximately 50% of unprovoked seizures recur [4] (therefore requiring follow up as per the definition of a chronic paediatric condition for this study) afebrile seizures of any kind were included.

Headaches

- Separated from other neurological conditions as headaches common and usually less severe.
- Includes migraines, chronic cluster and chronic tension headaches.

Other neurological

- Excludes epilepsy and headaches (covered in separate codelists).
- Includes other neurological disorders (e.g. cerebral palsy, paralysis, degenerative neurological disease, myopathies, dystonia, disease of myelination, neuropathy, hydrocephalus and intracranial vascular events).
- Includes congenital abnormalities of the brain / spinal cord and associated syndromes, neurological conditions of the perinatal period and presence of cerebrospinal fluid drainage devices.

Gastrointestinal

- Excludes cow's milk protein intolerance and gastro-oesophageal reflux without oesophagitis as very common and usually self resolving.
- Includes e.g. oesophagitis, inflammatory bowel disease, chronic liver disease and vascular disease of the intestine.
- Includes congenital gastrointestinal conditions (mouth, tongue, pharynx and gastrointestinal tract).

Genitourinary

- Excludes absence of single paired organs (e.g. unilateral renal agenesis).
- Includes e.g. glomerulonephritis, nephrotic syndrome, chronic kidney disease, renal infarct/thromboembolism and renal stones.
- Includes urinary incontinence as often seen long-term by urology / continence nurses.
- Includes cystostomies, urethrostomies, nephrostomies and dialysis devices.
- Includes congenital malformation of urinary system and genital organs, including indeterminate sex, hermaphroditism and pseudohermaphroditism.

Cancer (Malignant neoplasms)

- Excludes in situ neoplasms, benign neoplasms and neoplasms of uncertain or unknown behaviour.
- Read cancer codelist: https://phenotypes.healthdatagateway.org/concepts/C2023/version/5184/detail/
- SNOMED cancer codelist: https://phenotypes.healthdatagateway.org/phenotypes/PH960/version/2138/detail/
- SNOMED haematological cancer codelist (to supplement above) https://www.opencodelists.org/codelist/opensafely/haematological-cancer-snomed/2020-04-15/#full-list

Non-malignant haematological

- Excludes nutritional anaemias (very common), unspecified neutropenia, lymphopenia and thrombocytopaenia (broad categories which may be acute findings rather than diagnoses).
- Excludes disorders of neutrophil function and genetic disorders of leucocyte function (moved to immunological).
- Excludes haemophagocytic lymphohistiocytosis (moved to rheumatological).
- Includes e.g. haemolytic anaemias, aplastic anaemias and coagulation defects.

Immunological

- Includes e.g. immunodeficiencies, disorders of neutrophil function and genetic disorders of leucocyte function.

Chronic infections

- Excludes acute infections and tuberculosis.
- Includes HIV / hepatitis B / hepatitis C and congenital infections (syphilis / toxoplasmosis / rubella / herpes simplex virus and cytomegalovirus).

Rheumatological / musculoskeletal

- Excludes skeletal injuries / amputations and congenital malformations.
- Includes e.g. sarcoidosis, vasculitis, juvenile idiopathic arthritis and arthropathies.

Diabetes

- ICD-10 diagnoses as per Hardelid list.
- Read v2 codelist for diabetes: https://phenotypes.healthdatagateway.org/phenotypes/PH8/version/16/detail/
- SNOMED codelist diabetes: https://phenotypes.healthdatagateway.org/phenotypes/PH1006/version/2184/detail/

Other endocrine

- Excludes diabetes (see separate codelist).
- Includes e.g, hypothyroidism, hypopituitarism and adrenogenital disorders, congenital malformations of adrenal and other endocrine glands and disorders of calcium and phosphate metabolism.

Metabolic

- Excludes disorders of mineral metabolism.
- Includes e.g. disorders of amino acid, carbohydrate, sphingolipid, glycosaminoglycan, lipoprotein, purine and porphyrin metabolism.
- Includes conditions as per the ICD-10 chapter of metabolic disease, rather than for the specialty of Inherited Metabolic Disease (i.e. this codelist includes broader conditions), e.g. includes multisystem disorders such as amyloidosis and cystinosis.

Other congenital malformations and chromosomal abnormalities

- Excludes malformations of the respiratory tract, gastrointestinal tract, genitourinary tract, nervous system and endocrine glands (covered in respective system codelists).
- Includes multisystem congenital syndromes, malformations and chromosomal abnormalities not covered elsewhere.

Mental health disorders

- Serious mental illness ICD-10 codelist (F20.0-F31.9) as per Hardelid list (schizophrenia, delusional disorders, manic episode and bipolar disorder).
- Read serious mental illness codelist: https://phenotypes.healthdatagateway.org/phenotypes/PH558/version/1116/detail/#home
- SNOMED serious mental illness codelist: https://www.opencodelists.org/codelist/primis-covid19-vacc-uptake/sev_mental/v1/#full-list
- Remaining ICD-10 codes mapped using CALIBER.
- Includes anxiety, depression, somatoform disorders and eating disorders.
- Excludes dementia and simple phobias.

Neurodevelopmental and behavioural

- ICD-10 codelist for autism as per Hardelid list.
- Read v2 codelist for autism: https://phenotypes.healthdatagateway.org/phenotypes/PH110/version/220/detail/
- SNOMED codelist for autism: https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/quarter-3-october-to-december-2020-21/data-quality
- Includes e.g. learning disability, autism, hyperkinetic disorders, tic disorders and speech and language disorders.

Transplant

- Includes solid organ, cornea and bone marrow transplant and rejections.

Palliative care

- Includes CYP under care of palliative care team or seen in a hospice.

In cases where there was no agreement on the most appropriate grouping for a condition, the condition was retained within the parent ICD-10 group (e.g. amyloidoisis was retained under the metabolic subgroup).

Example methods for applying codelists to ICD-10, SNOMED and Read v2 datasets

The resultant 22 chronic paediatric conditions subgroups are shown in Table 1. For our analysis, conditions were considered active if they had been coded for in the preceding five years. A subgroup of chronic paediatric conditions were considered permanent, therefore considered active if coded for at any time (Table 1).

Table 1 – Chronic paediatric conditions subgroupings.

Chronic paediatric conditions subgroupings	When considered active
Asthma	Coded in the last 5 years
Cystic Fibrosis	Permanent (coded any time)
Other respiratory	Coded in the last 5 years
Cardiovascular	Coded in the last 5 years
Epilepsy	Coded in the last 5 years
Headaches	Coded in the last 5 years
Other neurological	Coded in the last 5 years (except subgroup of cerebral palsy/ paralysis conditions considered permanent)
Gastrointestinal	Coded in the last 5 years
Genitourinary	Coded in the last 5 years
Cancer	Coded in the last 5 years
Non-malignant haematological	Coded in the last 5 years
Immunological	Permanent (coded any time)
Chronic infections	Coded in the last 5 years
Rheumatological / musculoskeletal	Coded in the last 5 years
Diabetes	Permanent (coded any time)
Other endocrine	Coded in the last 5 years
Metabolic	Permanent (coded any time)
Other congenital malformations and chromosomal abnormalities	Permanent (coded any time)
Mental health disorders	Coded in the last 5 years
Neurodevelopmental and behavioural	Coded in the last 5 years
Transplant	Permanent (coded any time)
Palliative care	Permanent (coded any time)

These codelists were produced for a specific study and it may be that other research groups would consider including conditions that have been excluded here. Codelists for these excluded conditions could be produced using a similar approach if required. Other research groups may also choose different time periods or criteria for considering conditions to be active.

These harmonised UK primary and secondary care chronic paediatric condition codelists are publicly available (https://github.com/opensafely/hdruk-os-covid-paeds/tree/main/analysis/codelists). We hope they will be useful to the paediatric research community and welcome suggestions for improvement.

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Chronic Paediatric Conditions Committee

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