ACEsinEHRs

Control documentation and instructions

Version 3
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https://acesinehrs.com/

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Users should cite the www.ACEsinEHRs.com library and the accompanying Lancet Digital Health publication in all research outputs, presentations and reports.

All code is shared without investigator support.

Acknowledgement

This research benefits from and contributes to the NIHR Children and Families Policy Research Unit but was not commissioned by the National Institute for Health Research (NIHR) Policy Research Programme. The views expressed are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research, the Department of Health and Social Care or its arm's length bodies, and other Government Departments.

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These files may be updated periodically, so we appreciate hearing feedback or additional information about how the library is being used.

Documentation control sheet

Over time, it may be necessary to amend parts of this document. This form will be updated whenever changes are made by the original author team.

Version	Date	Affected Areas Summary of Change	Prepared By	Reviewed By
1.0	May 17, 2022	ACE indicators officially published	Shabeer Syed	CPRU team
1.1	June 15, 2022	Modified – added extra "flags" to aid with algorithm implementation	Shabeer Syed	CPRU team
1.2	July 11, 2022	Expanded code list – added & mapped codes for HES outpatient & HES A&E	Shabeer Syed	CPRU team

2	July 1, 2023	"*Maternal*" labels were amended to "*parental*", as we published a new study that applied indicators to linked fathers.	Shabeer Syed	CPRU team
2.1	July 1, 2023	Updated IPV algorithm to include additional A&E assault codes	Shabeer Syed	CPRU team
3	Feb 3	Updated code lists include cross-mapped CPRD Aurum medcodes incl. SNOMED codes	Shabeer Syed	CPRU team

Abbreviations: CPRU= NIHR Children and Families Policy Research Unit

ACEs in EHRs library

The ACEsinEHRs library is an open-access resource of validated indicators and algorithms for identifying ACEs in routinely collected non-identifiable healthcare data of mothers, fathers and children presenting to GPs and hospitals from two years before birth to 11 years after birth. The library accompanies the paper published in Lancet Digital Health, *"Identifying adverse childhood experiences with electronic health records of linked mothers and children in England: a multistage development and validation study, (2022). Shabeer Syed, Arturo Gonzalez-Izquierd, Janice Allister, Gene Feder, Leah Li, Ruth Gilbert."*

Indicators and algorithms

We developed two measures of ACEs for electronic health records (EHRs):
- Domains (ie, grouped indicators) and;
- Indicators (ie, grouped codes or measures)
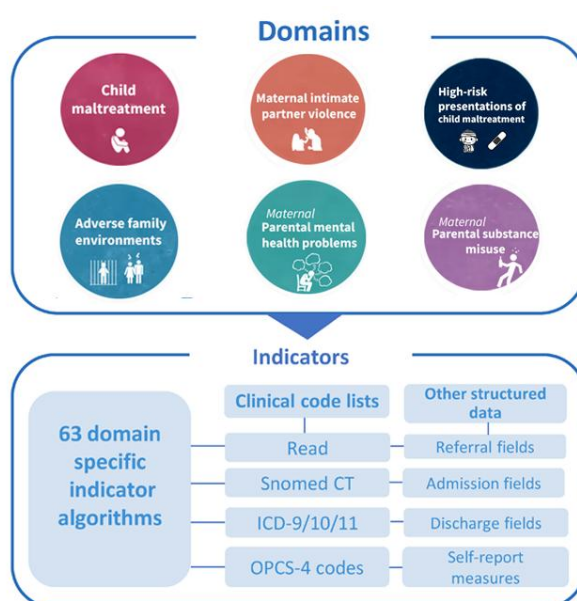
Most indicators are derived using algorithms that identify and extract information from EHRs using clinically coded healthcare information (for example, ICD-10, Read codes, SNOMED-CT). An overview of the algorithms is provided below in Table 2, and more in-depth descriptions are provided at www.acesinehrs.com/starterguide/. Rule-based algorithms are indicator-specific (mainly HRP-CM) and prevent misclassification, including age restrictions, exclusions of accidental injuries, genetic predispositions (bone diseases), traumatic birth injuries or maternal-child transmissions during birth (see below).

For GP records, we define indicators by combining information recorded in Read codes, prescriptions, referral fields and validated self-report measures (continuous variables needing re-coding) routinely administered by GPs or nurses (e.g. alcohol use).

For hospital and death registration records, we define indicators by combining codes from the International Classification of Diseases 9th/10th edition (ICD-9/10), the Classification of Interventions and Procedures (OPCS-4) and HES-APC discharge/admission fields. We also provide cross-mapped unvalidated indicators for newer systems (ICD-11/SNOMED CT) for further evaluation. Browse code lists here.

Unless specified, indicators refer to information recorded in both children's and parents' records.

Code lists

We provide mapped codes for each ACE indicator stored in code lists. Each data source will have different coding systems. The current ACEs indicators include ICD-9/10 codes (hospital/death records), Read codes, SNOMED-CT codes, medcodes, prodcodes, gemscripts (general practice), and codes for obtaining continuous data or coded information from speciality fields in CPRD GOLD, CPRD Aurum, HES-APC, HES-A&E and HES-OP.

We have converted several original codes so the code lists contain one column of research-ready codes. This ensures efficient information integration from multiple coding systems without accidental deduplication. See the code list dictionary in Table 1 below for more information.

File format

Code lists are provided as six separate text files (.txt) or one overall file that can be imported into standard statistical software and merged with a prepared data set to enable analyses of ACEs. This format maintains the correct values of each and

prevents programs like Excel from automatically converting values. The dictionaries are also available through the ACEsinEHR Code Browser and can be opened in Excel.

Downloads

All ACE indicators:
- [All ACEs (23164)](#)
- [All ACEs GP/CPRD GOLD/AURUM only: medcodes, prodcodes, measures only (20925)](#)
- [All ACEs Hospital only: ICD, OPCS and HES-APC specific fields (2239)](#)

By ACE domain:
- [Child maltreatment (1312)](#)
- [Intimate partner violence (972 including 519 codes for assault algorithm)](#)
  - [Intimate partner violence (453 - excluding codes requiring algorithms)](#)
- [High-risk presentation of CM (801)](#)
- [Adverse family environment (977)](#)
- [Parental mental health problems (3711)](#)
- [Parental substance misuse (1091)](#)

How to open code lists (text files) in Excel

Please note that opening code lists ".txt" files in Excel requires you to go to: "file" →"open" →"text files "→ import all columns as "text" in step 3 (see snippets below). This process ensures Excel retain the original code structure (e.g., otherwise excel removes leading zeros "0" from codes starting with 0).
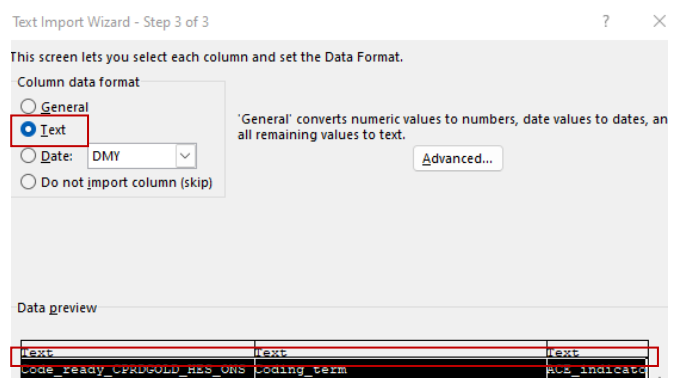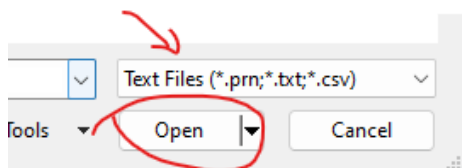
Table 1. Code list dictionary

Provided variable	Description
Code	Data ready code. Contains CPRD GOLD and CPRD Aurum medcodes and prodcodes (as used in the data provided by CPRD with added prefixes to prodcode), ICD-9/10 (removed punctuations for ICD), and OPSC-4 codes. Prefixes "*d_*" were added to the prodcodes, and "*p_*" to the OPSC-4 codes. Prefixes prevent deduplication of different codes, as different systems may use the same code for different descriptions.
Medcode_gold	Corresponding medcode in CPRD GOLD (cross-mapped with CPRD Aurum medcode)
Code original	Original code as entered into the respective system (removed punctuations for ICD)
Coding term	Original code description
Indicator code	Indicator code name
Indicator specific	Most specific indicator
Indicator 1	Main ACE indicator combining multiple codes or measures as used in validation paper
Indicator 2	Broader ACE indicator combining multiple codes or measures
Domain	ACE domain grouping all indicators (applicable for the overall code list)
Severity	Where applicable, this variable indicates the severity classification of the code description or medication dosage. *e.g. For alcohol misuse, "mild", "moderate", "severe". E.g. For medication, Fluoxetine, "20mg"*
Scale	1=Indicates that the code and severity classifications depend on extra clinical information (e.g. frequency of alcohol consumption). By default, this is set to *Mild* for alcohol. See rule-based algorithms.
Reference	1=code is part of family violence reference standard, 2=code can be used as a broader measure of family violence
Individual	1=code applies to child only, 2=code applies to mother only, 3=code applies to mother or child (i.e. either), 4=code only applicable to female children
Coding systems	GP/primary care: Read, OXMIS, Prodcode (prescriptions or items), CPRD REFERRAL FHSASPEC (field-specific), CPRD REFERRAL NHSSPEC (field-specific). HES-APC/secondary care/ONS: ICD-10, OPCS-4, ICD-9 (applies to ONS < year 2000), HES-APC DISDEST OR ADMISORC (field-specific)

Table 2. Rule-based algorithms by ACE domains

ACE domain	Indicator(s)	Rule-based algorithms
Parental SM	Alcohol misuse Severe	*Include if continuous data meets the cut-off assigned to each code (see code list):* e.g. AUDIT: ≥20; AUDIT-PC: ≥10; SADQ ≥31; ≥35 alcohol units per week (analogous to higher-risk drinking/harmful drinking/alcohol dependence; see NICE guidelines); >200 mg alcohol per 100 ml blood is classed as potential high-risk offender when driving in England/Wales (see UK gov) (applies to hospital admission codes in this study).
	Alcohol misuse Moderate	*Include if continuous data meets cut-off assigned to each code (see code list):* e.g. AUDIT: 8-19; AUDIT-PC: 5-9; SADQ 16-30; ≥15 to <35 units per week; *Men and women are advised not to drink more than 14 units per week (see increasing risk drinking/Alcohol Use Disorders as described by NICE);*[58, 59] <80 mg alcohol per 100 ml blood (Blood Alcohol Content) is the legal limit for driving in England/Wales (applies to hospital admission codes in this study).
Parental MHPs	Depression	*Include if continuous data meets the cut-off assigned to each code (see code list):* e.g. DASS-21 (sub-scales): ≥14; EDPS: ≥13; HADS (sub-scale): ≥11; HDRS (sub-scale): ≥ 14; PHQ-9: ≥10; SDS (Zungs's): ≥50
	Anxiety	*Include if continuous data meets the cut-off assigned to each code (see code list):* e.g DASS-21: ≥10; HADS (sub-scale): ≥11; HDRS (sub-scale): ≥18; SAS (Zungs's): ≥45 score; GAD-7: ≥8;
	Anxiety or depressive symptoms, antidepressants or anxiolytics and mental health service referral/interventions received	Codes referring to anxiety symptoms (e.g., worrying) or depression (e.g. "*feeling low*") were only considered a case of depression or an anxiety disorder when the patient was also given antidepressants and/or anxiolytic medication within 3-months or initiated psychological treatment within 2-years. Comparison estimates for mothers in CPRD-MBL with and without this algorithm are provided by Abel et al. [60] *Rule: Include symptoms/medications as an anxiety or depression indicator if a previous diagnostic code or tier 3 intervention code exists (within 2-years) or if there is a co-occurrence of a prescription consistent with a symptom within 3 months (e.g. anxiolytics & anxiety symptoms).*[61]
CM	FGM	*Apply codes mentioning circumcision to female children only (e.g. CPRD medcode "54314 - routine or ritual circumcision"). The code list includes markers for rule-based inclusions.*
Susp. IPV	Assault NOS (algo); IPV NOS (Assault and high-risk algo, 30/100 days)	Include as IPV if the assault recording co-occurs with any "*high-risk presentation recording*" 30 days before the assault or 100 days after the assault recording. High-risk recordings are a composite variable of recordings related to parental conflicts, health visitors being sent to the home, nurse partnership referrals, superficial head injuries and bruises. We developed the composite variable using results from our systematic review.[50] In the current study, the algorithm showed PPVs ranging from 18%-30% of definitive IPV (derivation cohort).
IPV	Assault NOS (algo), IPV NOS (Assault and preg. incident and CM algo, 45 days)	Include as IPV if assault recording co-occurs with any recordings of a safeguarding referral, child protection recording, definitive CM indicator, or "*pregnant state, incidental*" (marked in code list) within 45 days of the assault. UK guidelines state 45 days is the maximum timeframe for an initial outcome following a children's social care assessment from the date of received safeguarding referral (see point 82 in "*HM government. Working together to safeguard children*").[48]

HRP-CM	Child harm by undetermined intent; Lacerations, scars and abrasions; Thermal injuries; Unknown and unspecified causes of morbidity in child; Other and unspecified abdominal pain; Unspecified event in child; Obs for other suspected diseases and conditions in child	Include indicators as HRP-CM when excluding co-occurring accident-related injuries recorded within +/-15 days of the event. The required time interval for co-occurrences was selected based on the median time difference between data sources for some accidental injuries. Indicators were developed using NICE Clinical guideline [CG89]: 1.1.1-1.1.8; 1.1.15; 1.2.4, 1.2.5; 1.2.13.
	Eye trauma, NOS; Subarachnoid haemorrhage other; Subdural haematoma/retinal haemorrhage	Include as HRP-CM when excluded co-occurring accident-related injuries recorded within +/-15 days of the event, and when excluded, birth-related injuries recorded <2 days post-birth. Indicators were developed using NICE Clinical guideline [CG89]: 1.1.11; 1.1.10
	Fractures, Intra-abdominal injuries, spinal injuries, intracranial	Include as HRP-CM when excluded co-occurring accident-related injuries recorded within +/-15 days of the event, when excluded birth-related injuries recorded <2 days post-birth, and when excluded children with fragile bone disease (Osteoporosis), unless definitive CM is recorded within +/-30 days. Indicators were developed using NICE Clinical guideline [CG89]: 1.1.9; 1.1.12; 1.1.13
Studied outcomes		
MHP in children and adolescent	Self-harm, personality disorders, psychosis, substance use	The following minimum age restrictions applies to minimise misclassification: • self-harm ≥7 years • personality disorders ≥12 years • psychosis ≥10 years • substance use ≥12 years
	Neurodevelopmental conditions	Recorded neurodevelopmental conditions only retained when also associated with a mental health-related referral or intervention (i.e. could not alone meet criteria for a mental health problem).

Additional notes on indicator classifications:

Please note that some indicators may contain codes with descriptions that do not match the overall indicator name or its overarching domain. Some indicators may include codes with similar descriptions but are classified under different domains. This discrepancy occurs because codes were initially grouped into indicators based on the relevance of specific coding descriptions and iteratively re-classified based on frequency distributions, rule-based algorithms, intercorrelations and risk associations with the reference standard as described in the published paper. For instance, if the maternal record has a GP code termed "*Assault*", then the code is classified under the domain "*adverse family environments*" as an indicator labelled "*Mother assaulted, NOS (GP record only)*" because the mother's relationship status with the preparator cannot be determined, and because the code showed a relatively low-risk association with the reference standard. By contrast, if the maternal record has an ICD-10 code termed "*Assault in the home*", then the code is classified under the domain "*maternal IPV*" as an indicator labelled "*Suspected IPV, Mother assaulted NOS (hospital admission)*" because the assault occurred in the home (i.e. preparator more likely to have a relationship with the family) and because the code showed a relatively strong risk association with the reference standard.