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| **Code List Check List\*: Narcolepsy** | |
| **Metadata** | |
| Title | Narcolepsy |
| Name | narcolepsy |
| Authors | Helen Strongman, Tim Quinnell, Sofia Eriksson |
| Target data source | Clinical Practice Research Datalink Aurum (March 2023 and September 2023), GOLD (March 2023), linked Hospital Episode Statistics data |
| Terminology | Read (GOLD), SNOMED-CT (Aurum), EMIS (Aurum) and NHS 5th edition ICD-10 (HES). |
| **Definition of clinical concept** | |
| Concept | To identify all narcolepsy diagnoses |
| Timeframe | No restrictions |
| Accuracy | See validation study (referenced in resources published section) |
| Setting | Diagnoses recorded in primary care and hospital activity inpatient data |
| **Identify and evaluating existing code lists** | |
| Source searched | Google search using the term “cprd narcolepsy” and “cprd cataplexy” |
| Existing code lists found | None found |
| Verified by others | N/A |
| Verified by yourself | N/A |
| Existing code lists used | No |
| **Create a new code list** | |
| Synonyms | Narcolepsy, Cataplexy |
| Exceptions | None |
| Methods used | A script of lower-case search terms was used to identify relevant Read, medcodeid, snomedctconceptid in CPRD medical dictionaries and ICD-10 fields in NHS medical dictionaries. Terms anywhere in the string were identified. An additional search of Read Chapters was undertaken. |
| Search terms | Inclusion: narcolep, cataplexy  Exclusion: none |
| Hierarchy used to extend search | Inclusion Read Chapter: F27 |
| Decisions made while iterating | -An additional relevant code was identified: “Narcolepsy without cataplexy” in the September 2023 Aurum build.  -There were Read codes in chapter F27 with no associated observations/terms. These are not included in the codelist. |
| Categories | 1: Narcolepsy This category included terms with the string "narcolep” in the CPRD data dictionaries. Therefore, this category included terms containing both “narcolep” and “cataplexy”.  2: Cataplexy only This category included terms which included the string "cataplexy" but not "narcolep".  Cataplexy only codes are uncommon and were not included in definitions of narcolepsy for this study. |
| **Review, finalise and publish** | |
| Reviewers | Dr Sofia Eriksson (Neurologist & sleep specialist, University College London Hospitals NHS Foundation Trust and UCL): code list validity.  Dr Tim Quinnell (Respiratory & sleep specialist, Royal Papworth Hospital Trust) |
| Scope of review | The draft code list, search terms and exclusion terms were reviewed. |
| Evidence of review | The process is documented in HTML files:  (See “Resources published” section). |
| Internal checks | Undertaken by Helen Strongman |
| External checks | Validated in a study that used a questionnaire asking GPs to confirm secondary care (hospital) diagnosis/treatment for narcolepsy. This was used as the “Gold Standard” comparison to assess the CPRD codes identified (see resources published) |
| Code list published | The code list is published on the project’s LSHTM Data Compass page: <https://doi.org/10.17037/DATA.00004742>.  And in the study’s Github repositories at: <https://github.com/hstrongman/OSA-narc_CPRD_validation> (Aurum Sept 2023)  <https://github.com/hstrongman/OSA-narc-CPRD-chronology> (Aurum/GOLD March 2023)  Files include:  codelist\_narcolepsy\_aurum.txt  codelist\_narcolepsy\_aurum.dta  codelist\_narcolepsy\_gold.txt  codelist\_narcolepsy\_gold.dta  codelist\_narcolepsy\_hesapc.txt  codelist\_narcolepsy\_hesapc.dta |
| Resources published | Strongman, H., S. H. Eriksson, K. Asare, M. A. Miller, M. Sykorova, H. Mistry, K. Veighey, C. Warren-Gash and K. Bhaskaran (2025). "Validation of algorithms identifying diagnosed Obstructive Sleep Apnoea and narcolepsy in coded primary care and linked hospital activity data in England." medRxiv: 2025.2003.2010.25323660.  <https://www.medrxiv.org/content/10.1101/2025.03.10.25323660v1>  The Do files and HMTL documents describing the code list derivation and search strategy are in the study’s GitHub repositories  Files include:  codelist\_narcolepsy.do (refers to associated text files)  codelist\_narcolepsy\_description.html (early version of this checklist)  codelist\_narcolepsy\_derivation\_aurum.html  codelist\_narcolepsy\_derivation\_gold.html  codelist\_narcolepsy\_derivation\_hesicd.html |

\*Matthewman J, Andresen K, Suffel A, Lin LY, Schultze A, Tazare J, Bhaskaran K, Williamson E, Costello R, Quint J, Strongman H. Checklist and guidance on creating codelists for routinely collected health data research [version 2; peer review: 3 approved]. NIHR Open Res. 2024 Sep 18;4:20.