



Ymchwil Iechyd
a Gofal **Cymru**
Health and Care
Research **Wales**

Research Data Registries

March 2020



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Ariennir gan
Lywodraeth Cymru
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Research Data Registries

| REC Reference | Database name |
|---------------|---|
| 16/LO/1093 | A National Neonatal Research Database |
| 17/YH/0325 | A national surveillance study of inherited white matter disorders |
| 11/NW/0187 | Advanced Stent-Graft Techniques for Aneurysm Repair |
| 10/H1010/51 | Aintree Liver Resection Database |
| 14/NE/1200 | Airway Intervention Registry (AIR) |
| 09/WSE02/54+5 | All Wales Perinatal Survey |
| 13/EM/0007 | Analysing the Galatean Risk and Safety Tool (GRiST) Database |
| 14/LO/0383 | ASSERT 2 Database (Version 1) |
| 11/LO/0253 | Assessment of effectiveness of ESWT for soft tissue injuries (ASSERT) |
| 17/SW/0107 | Barts Health:NICOR - Extended Use of Data |
| 16/SW/0312 | BNFL worker epidemiology study |
| 17/LO/0971 | Breaking Free from Smoking - Research Database |
| 12/LO/0076 | Breaking Free Online Research Database |
| 10/H1102/86 | British Childhood Cancer Survivor Study (BCCSS) |
| 09/H0405/48 | British Isles Network of Congenital Anomaly Registers |
| 17/NW/0185 | BSET GLOBALSTAR v2.0 |
| 17/EE/0346 | BTS Idiopathic Pulmonary Fibrosis and Sarcoidosis Registry |
| 17/LO/1539 | BTS Multidrug-resistant Tuberculosis Clinical Advice Service Database |
| 09/H0810/16 | CALIBER Version 1 |
| 16/WS/0203 | Childhood Epileptic Encephalopathies Database |
| 16/SC/0346 | Clinical Endocrine Registry |
| 11/SW/0209 | Collaborative Neonatal Dataset (CONED) |
| 12/SC/0029 | DARLInG Database Version 1 |
| 17/YH/0278 | dREAMS |
| 17/LO/0449 | ECCI cCMV Database |
| 11/LO/0567 | Education and Research Database for healthcare communication |
| 12/SC/0532 | Epidemiological studies using the case and control data of the NRCT |
| 12/SC/0499 | Epidemiology and outcome from Out of Hospital Cardiac Arrest (OHCA) |
| 09/H1310/49 | Epidemiology of childhood ataxias |

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| 15/EM/0038 | European Network of Rare Bleeding Disorders: PRO-RBDD |
| 11/NW/0339 | Evaluation of the new "Fit Note":construction of national database V1 |
| 12/NE/0398 | Familial Hypercholesterolaemia Paediatric Register |
| 16/ES/0094 | Genetic Skin Disease in Scotland |
| 13/NE/0266 | Global FKRP Registry |
| 10/H0308/26 | Glycogen Storage Disease VI and IX Registry |
| 13/LO/0329 | Hairy cell leukaemia patient registry and clinical database |
| 15/WA/0076 | HealthWise Wales |
| 10/H0405/25 | Healthy Living in ProtecT participants (HeLPP): use of data v1 |
| 16/SC/0377 | Improving outcomes from the treatment of back pain |
| 12/NW/0759 | Inception Cohort for juvenile systemic scleroderma |
| 09/H0606/108 | Inherited Cardiac Conditions UK register (UK GenetICC) |
| 11/EM/0311 | International Epilepsy Database (version 2) |
| 13/WS/0220 | International Fetal Cardiac Intervention Registry |
| 14/NE/0116 | International NCL Registry (UK) |
| 09/H1102/1+5 | LATTE: Long-term Anastrozole vs Tamoxifen Treatment Effects |
| 16/EM/0440 | Linked de-identified research database for congenital anomaly outcomes |
| 15/LO/0810 | MND Register for England, Wales and Northern Ireland |
| 15/SW/0140 | Mortality and cancer registration for the Boyd Orr cohort. Version 1 |
| 15/NE/0390 | Myotubular and Centronuclear Patient Registry |
| 16/SW/0313 | National Registry for Radiation Workers (NRRW) |
| 14/SW/1088 | National Registry for Rare Kidney Diseases (RaDaR) |
| 05/Q0806/34+5 | Neonatal Infection Surveillance Database (neonIN) |
| 12/SW/0368 | Non-interventional Study of Pasireotide sc Study in Cushing's Disease |
| 17/SC/0001 | NRCT Research Database v 1.0 |
| 15/EM/0150 | Optimum Patient Care-Research Database (OPC-RD) |
| 12/SW/0273 | Patient Outcomes Registry |
| 16/SC/0374 | Perioperative Quality Improvement Programme (PQIP) |
| 17/LO/0973 | Pillars of Recovery assessment site - research database |
| 12/EM/0001 | P-Medicine: Data sharing and integration for personalised medicine |
| 12/SW/0326 | PPCI Registry Feasibility Study |

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| 14/SC/0093 | PreDiCT-TB: Model-based preclinical dev. of TB drug combinations v1 |
| 16/ES/0093 | Preterm Clinical Network Database v.1 |
| 10/H1010/14 | Prospective CML registry in Northern England & Wales for EUTOS |
| 10/H0903/53 | Prospective Hyponatremia Registry |
| 13/EM/0044 | QSurveillance Database |
| 17/WM/0343 | Rectal Cancer Oncological Complete Response Database (OnCoRe) |
| 17/NS/0066 | Register for asthma research (REACH) |
| 15/LO/1327 | Registry for Patients with Niemann-Pick Type C Disease |
| 17/SS/0050 | Registry for Patients with Niemann-Pick Type C Disease (Scotland 2) |
| 09/H1102/16+5 | Research register for transient neonatal diabetes 2014-2019 version 1 |
| 17/LO/0049 | Research using the National Chronic Kidney Disease Audit data |
| 15/WA/0229 | Rett Syndrome Registry for the UK (RSRUK) |
| 09/H1010/2 | Risk modelling for aneurysm surgery 1.0 |
| 09/H1010/1 | Risk modelling for carotid surgery 1.0 |
| 13/WS/0148 | Searchable Online Database for MRC UK Brain Banks Network |
| 17/SS/0044 | Service User Researcher Database |
| 17/LO/0846 | Small Area Health Statistics Unit (SAHSU) |
| | Stroke Hub Wales |
| 15/LO/0499 | TATME database |
| 16/LO/0895 | Teenage and Young Adult Cancer Survivor Study (TYACSS) |
| 17/LO/1098 | The ACPGBI Robotic Registry |
| 14/SS/1101 | The European Bronchiectasis Registry |
| 17/NW/0129 | The Health and Occupation Research Network |
| 14/WS/1050 | The I-DSD Registry v2.0 |
| 16/SW/0194 | The UK Multiple Sclerosis Register |
| 15/NW/0449 | The UK National Registry of Chronic Myeloid Leukaemia (CML) |
| 16/NE/0042 | The UK Renal Registry: a research database |
| 12/WS/0277 | The Virtual International Cardiovascular and Cognitive Trials Archive |
| 12/SW/0272 | TROPHY |
| 12/WA/0159 | TSC European Disease Registry Study (TOSCA) |
| 11/LO/1144 | UK Endocarditis Research Database |

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| 13/NE/0048 | UK FSHD Patient Registry |
| 11/EE/0041 | UK Gastrointestinal Stromal Tumour (GIST) Registry |
| 12/SC/0260 | UK IBD twin database |
| 13/LO/0199 | UK Ileal pouch registry |
| 17/EM/0015 | UK LAM Registry |
| 11/SW/0160 | UK Multiple Sclerosis Register |
| 11/NE/0179 | UK National Registry for Myotonic Dystrophy v1.0 |
| 16/SW/0314 | UK Nuclear Weapons Test Participants Study (NWTPS) |
| 10/H0717/110 | Use of urinary steroid profile data for research. Version 1 |
| 09/H1010/2+5 | Vascular Governance North West Database (VGNW) |
| 14/WA/1177 | Virtual Physiological Human VPH-Share |
| 11/EM/0189 | West London Premature Ovarian Failure Database |
| 17/LO/1666 | WMUK Registry |
| 17/NW/0530 | X-Linked Hypophosphatemia Registry |