



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

Research Directory

Research Data Registries

March 2020



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Ariennir gan
Lywodraeth Cymru
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Welsh Government

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

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

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

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